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An Interpretative Phenomenological Analysis of the Experience of Receiving a Diagnosis of Bi-Polar Disorder

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Volume 1

Main Project & Service Evaluation Project

Kasper Sandgaard Pallesen

Institute of Psychiatry

King's College London

2009-2012

**Submitted in Partial Fulfilment of the Degree of Doctorate in Clinical
Psychology**

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Main Project

An Interpretative Phenomenological Analysis of the Experience of Receiving a Diagnosis of Bi-Polar Disorder

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Institute of Psychiatry

King's College London

2009-2012

Supervised by Dr June Brown and Dr Diana Rose

Submitted in Partial Fulfilment of the Degree of Doctorate in Clinical Psychology

Abstract

There is a significant gap in the literature in relation to the experience of receiving a psychiatric diagnosis and in particular, in relation to receiving a diagnosis of bipolar disorder. The present study therefore aimed to get an in-depth understanding of the experience of receiving a diagnosis of bipolar disorder. Specific areas of interest were participants' subjective experience of receiving a diagnosis of bipolar disorder, participants' understanding of their diagnosis, participants' experience of how well (or not) the diagnosis fitted their experiences, participants' perceived consequences of having a diagnosis and any particularly helpful or unhelpful aspects in relation to the way the diagnosis was imparted. In collecting and analysing data, this study aimed to utilise a qualitative cross sectional design set within a social constructionist framework. Semi-structured interviews were carried out and transcripts were analysed using IPA (Smith & Osborn, 2003; Smith, 2007; Smith et al. 2009). A purposive sample of service users was used, in keeping with IPA requirements to have a small and fairly homogenous sample. The sample consisted of seven women and two men all of whom had received a diagnosis of bipolar disorder within the last year. The reported findings are based on the participants' accounts of their experience of receiving a diagnosis of bipolar disorder and the meaning they attach to this experience, as well as the researchers' own interpretation of these accounts. In essence, the findings can be described in terms of three master themes: 1. 'Establishing fit between the diagnosis and subjective experiences', 2. 'Evaluating the utility of carrying the diagnostic label' and 3. 'The role of diagnosis in searching for solutions for one's difficulties'. While these results broadly support findings from previous studies, they differ in terms of the central position of the process of establishing fit between diagnosis and personal experiences and in terms of the relevance of perceived stigma for this particular group of participants. The study also highlights the importance of the role of the client-clinician relationship in terms of establishing fit and instilling hope which has implications for the acceptance of the diagnosis and engagement with services. Finally, further implications and directions for future research are discussed.

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1. Introduction

1.1. Psychiatric Diagnosis

1.1.1. Classification of Mental Health Disorders

The difficulties of patients with mental health problems are usually categorised by diagnoses. According to Guha (2010), the categorisation of mental health disorders dates back to medieval times, with the distinction between ‘Idiocy’ (learning disability), ‘Lunacy’ (mental disorder) and ‘Palsy’ (neurological disorder) being made. In psychiatry, the two most commonly used systems for the classification of mental health disorders are the Diagnostic and Statistical Manual of Mental Disorders fourth edition (DSM-IV) and the International Statistical Classification of Diseases and Related Health Problems tenth edition (ICD-10). The coding systems used in the DSM-IV and the ICD-10 are developed to be compatible, although not all codes match at all times as the two publications are not revised simultaneously. Both manuals claim to identify and describe symptoms of discrete mental health disorders and aim to be atheoretical and symptom-based, in order to avoid conflict with the description of disorders proposed by different theoretical orientations. In addition, the framework of understanding psychiatric disorders provided by the DSM-IV and the ICD-10 assumes, according to Lakoff (2005), that disorders are stable entities that transcend their embodiment in, and meaning for, any individual patient.

1.1.2. Benefits of Diagnostic Systems

A number of benefits of having a diagnostic system have been highlighted. Lakoff (2005) argues that having an internationally shared rule-based framework for diagnostic classification can ease the task of developing and operationalising reliable treatment and research protocols. Furthermore, by using diagnostic systems to guide treatment and research, mental health professionals are able to maintain a degree of consistency in their practice. Jablensky (2012) argues that the use of such systems increases diagnostic agreement among clinicians and reduces the scope for idiosyncrasies in the treatment of psychiatric disorders. In addition, Jablensky (2012) points out that having a common framework can also facilitate communication between mental health professionals, service users and carers by demystifying psychiatric diagnosis and making its logic transparent to non-professionals.

Service users themselves may also find comfort in knowing that diagnosis, assessment and treatment are not solely based on subjective opinions of a clinician. In addition, some regard the formulation and sharing of a psychiatric diagnosis as therapeutic in itself, in that psychological symptoms can be given meaning and effectively discussed with the service user (Brody & Waters, 1980). In this way diagnoses might be useful in providing both service users and their families with the recognition that their symptoms are ‘real’ and that there may be available treatments for them.

There are other societal benefits of diagnostic systems. Psychiatric diagnosis is, according to Cassell (1976), generally accepted by society as a valid reason for feeling distress and for determining who will have access to health and social services. In addition, Psychiatric diagnosis may determine who can be considered by insurance companies for payouts. Psychiatric diagnosis is also used within the legal system where individuals with mental health difficulties who commit crimes may be considered for alternative sentencing. Without such guidelines, it could be easier for criminals to feign a mental illness in order to receive lighter sentences. Furthermore, other legal benefits can also be extended to individuals who require support based on their diagnosis and to protect people who lack mental capacity.

According to Jablensky (2012), the advantages of having explicit diagnostic criteria and a rule-based classification system outweigh the alternative of having no such universal framework. However, not everyone shares this view and the frameworks provided by the ICD-10 and DSM-IV have also received substantial criticism over the years.

1.1.3. Criticisms of Diagnostic Systems

One of the main criticisms of psychiatric diagnosis comes from the anti-psychiatry movement, which emerged throughout the 19th and 20th centuries as a reaction to the institutionalisation of people with mental health difficulties (Kutchins and Kirk, 1997). During the 1960s it gained further momentum, partly due to the work of philosophers such as Foucault (1976, 1988) and Laing (1961, 1969) and anthropologists such as Benedict (1967). The main argument was that mental illness was a way for society to label and control people who behaved outside of the norms of that given society or culture. Kutchins and Kirk (1997) made the argument that the categories of mental illness described in the DSM-IV were politically motivated and as such did not reflect valid disorders. They claimed that “the DSM simply pathologises those in society who

are undesirable and powerless ... because of unspoken cultural biases about what should be considered normal and what should be considered disease” (Kutchins & Kirk, 1997). Historically there have been several examples of how psychiatric diagnoses have been used to oppress people in marginalised groups. One such example is the diagnosis of drapetomania described by Sharkey (1994), in which slaves in America were supposed to have a mental illness that caused them to possess an irrational desire for freedom and a tendency to flee captivity (Sharkey, 1994).

Kutchins and Kirk (1997) also touch on another issue with the current diagnostic systems, namely the issues of defining normality and distinguishing normal, non-pathological distress from disordered distress. Benedict (1967) argued that diagnostic categories are always culturally determined and that each society develops its own ideas about the location of the threshold between normal and abnormal and determines which behaviours to place on either side of the boundary. According to Kutchins and Kirk (1997), the difficulty in making such distinction is that intense normal distress often looks, in terms of overt manifestations, like the symptoms of disordered or pathological distress. They argue that it is the context rather than the symptoms themselves that reveal when a psychiatric disorder is present or not. In their critique, they point in particular to the shift to more symptom-based diagnostic criteria which was introduced with the publication of the DSM-III and argue that this has exacerbated the difficulty of distinguishing normal from disordered distress. In addition, according to Wakefield (2010), basing diagnosis solely on the presence of symptoms has created the issues of false positive diagnoses (diagnoses that, on the basis of symptoms, mistakenly suggest the presence of a disorder when it is not present). An attempt was made to reduce false positive diagnoses from the DSM-IV by incorporating a ‘clinical significance’ criterion to most disorders, which states that symptoms must cause significant distress or impairment in functioning for a disorder to be diagnosable (Wakefield, 2010). However, Wakefield (2010) argues that the false positives created through the use of symptom-based diagnostic manuals such as the DSM-IV and the ICD-10 are most often due not to a failure of symptoms to reach a threshold of significant distress or impairment in functioning, but due to a failure to identify a ‘symptomatic’ criteria that indicate an underlying dysfunction or disorder that is different from symptoms of normal distress.

A contemporary critique of psychiatric diagnosis comes from Mary Boyle. In an article entitled 'The Problem with diagnosis', Boyle (2007) proposes a number of arguments for why mental health professionals should abandon their use. Her main point is that psychiatric diagnoses lack a scientific basis because they are based on the inaccurate assumption that behaviours and emotions, like bodily complaints, can be understood as visible manifestations of a unified underlying dysfunction or syndrome. Like Kutchins and Kirk (1997), Boyle (2007) proposes that the use of theoretical frameworks developed for bodily symptoms to explain and understand psychological difficulties were accepted for political rather than scientific reasons. Furthermore, she points out that not only have psychiatric diagnoses survived in spite of lack of empirical evidence for them but also that they distort the way in which research is being carried out. One way in which the reliance of diagnostic systems distorts research is, according to Boyle (2007), through the introduction of ideas such as dual diagnosis or co-morbidity. She argues that these ideas have come to light in order to account for the fact that psychiatric diagnoses have proven a poor predictor of behaviours and that these behaviours and emotions rarely fit into succinct diagnostic categories. Another way in which diagnostic categories distorts research is, according to Boyle (2007), by prioritising 'form over content' (such as focusing on the presence or absence of hallucinations rather than what the content of the hallucinations or what they mean for the individual. Boyle (2007) points out that by doing so, psychiatric diagnoses neglect large areas of human experience. Finally she argues that psychiatric diagnoses also distort research by defining its participants as ill and fundamentally different from the general population as opposed to seeing psychological distress as understandable responses to adverse circumstances and relationships. Finally, Boyle (2007) also points out that the reliance on psychiatric diagnosis has the unhelpful side-effect that blame for psychological distress often tends to be attributed to the individual at the expense of considering the role of environmental factors in the development of psychological difficulties.

Another contemporary critic of the use of diagnostic systems in psychiatry is Richard Bentall. In a joint article with David Pilgrim (Bentall and Pilgrim (1999), Bentall adopts a position as a critical realist and as such positions himself between a social constructivist / anti-psychiatrist view that mental health difficulties are predominantly a consequence of power imbalances and discursive practices and a medical naturalism view. He argues that mental illness itself is not socially constructed, rather it is the theories of mental illnesses and the methodological priorities deployed to investigate

them which are shaped by social forces and informed by interests. He offers the following critiques of the current diagnostic systems. His first main critique pertains to their perceived usefulness, legitimacy and validity. Bentall is particularly critical of the usefulness of the concept of schizophrenia and argues, like Boyle (2002, 2007), that it is largely socially constructed and that it exists more for political and economic reasons rather than because it represents a real syndrome. In addition, he argues that clinically, there is little need for such classification because it is more meaningful for clinicians to address the specific symptoms and difficulties that people experience in the context of the relationships they find themselves in. Secondly, he criticises the emphasis on biological causes for mental illness and the over-reliance of medication at the expense of psychosocial causes such as poverty, child abuse and trauma. In particular he criticises the quality of the early genetic studies which were pivotal in shaping current understanding of schizophrenia as a biologically based illness and that more recent studies fail to show the same high concordance of psychosis in monozygotic twins. Although Bentall (1999) is critical of the current diagnostic systems, he positions himself in favour of the idea of a useful scientific and meaningful diagnostic classification system for mental health difficulties but argues that the DSM or ICD do not represent such frameworks as they are based on flawed assumptions, have little predictive value and is clinically of little use.

A final point is offered by Bolton (2010). He argues that apart from the pressures of being able to define normality and differentiate normal distress from disordered distress, clinicians are also faced with a number of other pressures which puts the validity of psychiatric diagnosis further into question. One such pressure comes, according to Bolton (2010), from drug companies. He argues that because there are large profits to be made from drugs used in repeat prescriptions for on-going chronic disorders, there is a risk of clinicians being pressured into pathologising normal life stresses. Another pressure comes from insurance companies. Bolton (2010) argues that the introduction of the 'clinical significance' criteria in diagnostic manuals comes in part from the need for insurance companies to have clear cut-off points to assist them in deciding what to pay out for. Finally, he argues that academic institutions are also 'keen on' psychiatric labels, especially when funding follows them.

1.2. Bipolar Disorder

1.2.1. Definition and Critique of the Concept of Bipolar Disorder

According to the ICD-10, bipolar disorder is characterised by at least two episodes where a person's mood and activity levels are significantly disturbed, this disturbance consisting on some occasions of an elevation of mood and increased energy and activity (mania or hypomania), and on others of a lowering of mood and decreased energy and activity (depression). Episodes of both kinds often follow stressful life events, but the presence of such stress is not essential for the diagnosis. The first episode may occur at any age and the frequency of episodes and the pattern of remissions and relapses both vary. According to Akiskal and Benazzi (2006), there is no clear consensus as to how many types of bipolar disorder exists and in both the ICD-10 and the DSM-IV, bipolar disorder is described as a spectrum disorder. In the DSM-IV (American Psychiatric Association, 1994), in addition to having experienced episodes of elevated mood and depressed mood, a person must also experience at least three of the following symptoms in order to qualify for a diagnosis of bipolar disorder: 1. Inflated self-esteem or grandiosity, 2. Decreased need for sleep, 3. Flight of ideas, and 4. Distractibility. The DSM-IV also includes a severity criteria for mania and hypomania and states that for an episode to be classed as a manic episode it must cause marked impairment in functioning and that a hypomanic episode must involve a clear change in functioning that is uncharacteristic of the person when not symptomatic (American Psychiatric Association, 1994).

When looking closer at the criteria set out in the DSM-IV and the ICD-10, it has been noted that a diagnosis of bipolar disorder can be given based on psychiatric history as opposed to current symptomatology and functioning (Mansell & Pedley, 2008). This means that, technically, anyone with a history of (hypo) mania and depression can receive a diagnosis of bipolar disorder. This has been described as an ethical and methodological issue by Mansell and Pedley (2008) as it means that no one who has received a diagnosis of bipolar disorder can ever be considered as having recovered from it, rather, they can only be considered to be in remission. This is considered especially problematic given that brief hypomanic episodes are widespread among people generally and not necessarily associated with dysfunction (Mansell & Pedley, 2008).

1.2.2. Prevalence of Bipolar Disorder and Co-morbidity

The lifetime prevalence of bipolar disorder is fairly consistent across different countries with rates of 0.3% in Taiwan (Weissman et al., 1996), 1.5% in New Zealand (Weissman et al., 1996) and 1-2% in the United States (Kessler et al., 1999). It is equally prevalent in men and women and is found across all cultures and ethnic groups (Godwin and Jamison, 1990). Worldwide, bipolar disorder is the sixth leading cause of disability (Murray & Lopez, 1996) and bipolar disorder is considered one of the most incapacitating disorders in the United States (LaPlante, 2002). In addition, there is a high rate of mortality in people whose bipolar disorder goes untreated (Keck, McElroy, & Stakowski, 1998) and it is estimated that approximately 25% of people with bipolar disorder have attempted suicide (Dilsaver, et al., 1994).

Bipolar disorder often co-occurs with other psychiatric disorders and according to McElroy (2001), people with a diagnosis of bipolar disorder was twice as likely to also have another lifetime axis I psychiatric disorder. In addition, epidemiological data suggest that the rates of substance use and anxiety disorders in people with bipolar disorder are significantly higher than in the general population (Regier et al., 1990; Brady, 1992; Strakowski et al., 1994). Further studies suggest that bipolar disorder may also frequently co-occur with eating disorders (Strakowski et al., 1992; Kruger et al., 1996).

1.3. Stigma

Psychiatric diagnoses are often accompanied by feelings of stigma and experiences of discrimination. As a result, many of the studies on diagnoses have often focused on the associated stigma (Hayward and Bright, 1997). According to Lysaker (2008) it is important to consider peoples' experiences of stigma as they can have a negative impact on self esteem. In addition, experiences of stigma might also have a negative effect on the recovery process (Dinos, 2002; Camp et al, 2002). Van Os (2010) argues that psychiatric diagnosis should only be used if it is acceptable to those who are invited to carry its label. This next section outlines a brief history of stigma associated with mental illness followed by a discussion of the current understanding and impact of stigma.

1.3.1. Brief History of Attitudes towards People with Mental Illness

In Europe during the Middle Ages, ‘madness’ (the term used then) was seen as either a sign of losing religious faith or of being in possession of a demon (Porter, 2002). People with mental health difficulties were often punished or tortured in order to reach spiritual goals or be ridded of demons. Towards the end of the Middle Ages, these beliefs were on the decline but people with mental health problems were still looked down upon and often treated similar to beggars or criminals (Porter, 2002). During the Renaissance, the explanations for madness began to change from the supernatural towards the medical and people with mental health problems started to be viewed as ill and needing treatment, rather than being supernaturally possessed (Porter, 2002). In some circles there was an even further shift in attitudes, with artists and poets contending that true knowledge could only be found in madness (Porter, 2002).

The idea that people with mental health problems should be treated with kindness and sympathy took hold in the United States in the early 19th century. During this period, a large number of asylums were built to provide moral treatment to ‘insane’ people. However, over time, this treatment became too expensive to maintain and asylums reverted to institutions of control through the use of punishment and violence (Porter, 2002). In the second half of the twentieth century, attitudes toward people with mental health difficulties shifted again with the development of antipsychotic medication and the promise of a complete cure for people with disorders such as bipolar disorder (then manic-depression) and schizophrenia (Porter, 2002). This, along with the rebirth of the antipsychiatry movement, resulted in a mass deinstitutionalization of people with mental health difficulties into the community. In addition, treating people with severe mental health difficulties in the community, instead of in hospitals as inpatients, was seen as being a more cost effective solution (Borus, 1981).

1.3.2. Definition of Stigma

Stigma was first defined by Goffman (1963) who described it as ‘a spoiled identity that discredits a person in society’, and later by Crocker (1998) as ‘the possession of attributes that convey a social identity devalued within particular social contexts’. Corrigan (2004) distinguishes between two types of stigma, public and self-stigma. According to Corrigan (2004), public stigma can be seen as ‘harm to an individual’s social opportunities. He argues that stereotypes (such as ‘all people with mental illness are dangerous’), prejudice (such as ‘I agree that people with mental illness are

dangerous and I am afraid of them’), and discrimination (such as ‘I don’t want to be near them; don’t hire them at my job’) can rob people labelled mentally ill of important life opportunities that are viewed as being essential for achieving life goals. Self-stigma occurs when members of a stigmatised group internalise the public stigma. This form of stigma results from people with mental health difficulties accepting societal stereotypes and prejudice about people with mental illness and applying these to their own situation. This can lead to self-discriminatory beliefs (such as ‘why should I apply for a job when I am incompetent’) which ultimately has a negative impact on self-esteem, self-efficacy and confidence in one’s future. Research into both types of stigma will be the focus of the next sections.

1.3.3. Public Stigma and Discrimination

Hayward and Bright (1997) conducted a literature review to summarise the extent and nature of psychiatric stigma. They found that many studies supported the view that a label of a psychiatric illness is stigmatising. Early studies generally reported that lay people feared, disliked and wished to avoid people with mental health difficulties (Hayward and Bright, 1997). A particularly influential study by Cumming & Cumming (1957) aimed at measuring attitudes towards people with mental health difficulties and offering psycho-education to facilitate change was forced to discontinue due to hostility from the local community. Furthermore, Nunnally (1961) concluded that lay people were not so much misinformed as uninformed about mental illness and found that lay people held beliefs and attitudes towards people with mental health difficulties such as being dirty, unintelligent, insincere, and worthless. More recent studies show some evidence of increasingly positive attitudes towards people with mental health difficulties (Brockington *et al.*, 1993; Flaskerud & Kviz, 1983) but many studies continue to report stigmatisation of mental illness. For example, Wahl (1999) conducted a survey of 1,301 mental health consumers concerning their experience of stigma and discrimination. Participants in this study reported experiencing stigma from a variety of sources, including communities, families, churches, co-workers, and mental health caregivers. The most commonly reported experiences involved witnessing stigmatising comments or depictions of mental illness and almost 80% of respondents indicated that they had overheard people making hurtful or offensive comments about mental illness.

More direct experiences of overt stigma and discrimination are also frequently reported. Research over the past four decades has shown that individuals diagnosed with a psychiatric diagnosis are overtly discriminated against in several ways by key individuals in their social networks and communities. For example, studies have found that employers (Farina 1978; Link, 1982, 1987), families of patients (Struening, 2001), mental health workers (Cohen, 1962), and prospective landlords (Page, 1995; Wahl, 1999) all endorsed devaluing statements about or discriminated against individuals with mental health difficulties. Furthermore, other studies have found that people showing signs of mental illness are more likely than others to be arrested by the police (Teplin, 1984) and to spend more time incarcerated than those without mental illness (Steadman, McCarthy, & Morrissey, 1989). Overt discrimination is also observed in the general health care system. Desai, Rosenheck, Druss, & Perlin (2002) carried out a study looking at archival data which suggested that people with mental health difficulties received fewer medical services than those not labelled in this way. In addition, Wahl (1999) found that the majority of respondents in his study noted that they had been treated as less competent by others once their illness was known. He also found that 27% of the respondents found themselves often being advised to lower their expectations in life and to accept jobs well below their educational and intellectual level. Furthermore, he reported that 32% of respondents had been turned down for a job for which they were qualified after their mental health diagnosis was revealed and that even when successful in getting a job, 28% of participants found their work environment to be unsupportive and unfriendly after disclosing their diagnosis.

1.3.4. Self-Stigma

Research has shown that people with mental health difficulties often internalise stigmatising ideas that are widely endorsed within society and believe that they are less valued because of their psychiatric disorder (Link, 1987; Link & Phelan, 2001). Link (1989, 1999) and colleagues have argued that because of this internalisation, people with mental health difficulties develop coping strategies such as secrecy about their illness or withdrawal from social interaction in an effort to avoid anticipated discrimination and rejection. Further studies have shown that self-stigma can have a negative impact on self esteem. Lysaker (2008) found that participants who accepted stereotyped beliefs or who had greater levels of withdrawal as a result of stigma tended to view themselves as less lovable, less competent and tended to have less moral self-approval.

However, according to Camp et al. (2002) the relationship between public stigma and low self esteem is neither straightforward nor inevitable, and there is evidence suggesting that negative consequences may not necessarily occur. He found that although participants were aware of society's unfavourable representations of their mental illness and on the effects this had on their lives, they did not accept these representations as valid and therefore rejected them as applicable to the self. This research illustrates the importance of considering people's subjective understandings of stigmatised conditions in order to understand the relation between public stigma, self stigma and self esteem. Camp et al. (2002) conclude that the relationship has not been sufficiently theorised, and that a more detailed analysis is called for in order to understand the relationship between stigma and the self. Apart from the potentially damaging effect of self-stigma on self esteem, many studies have attempted to illustrate the detrimental effects and consequences of stigma in general.

1.3.5. Effects of Stigma and Discrimination

In a study by Dinos et al. (2004) using narrative interviews, the most common consequences of stigma and overt discrimination were anger, depression, fear, anxiety, feelings of isolation, guilt, embarrassment and prevention from recovery. Wahl (1999) interviewed 100 people with a range of psychiatric diagnosis including bipolar disorder, schizophrenia, and major depression, on the consequences of experiencing stigma relating to their diagnosis. He found that the most commonly reported emotional reactions to stigma experiences were anger (33% of participants), hurt (28%), sadness (18%), and discouragement (17%). In addition, findings showed that experiencing stigma had a number of lasting effects. More than half (57%) reported lowered self-esteem and loss of confidence in themselves. 39% reported that their experiences had made them less likely to disclose information about their disorders, more likely to avoid social contact (31%) and less likely to apply for job or educational opportunities (21%). In addition, 27% of participants reported lasting effects on their feelings about and expectations of others, less trusting of others and more guarded. Finally, 14% reported that their stigma experiences had contributed to the persistence of symptomatic emotional symptoms such as anxiety and depression. This is echoed by Rüsch et al. (2005), who argued that the consequences of stigma may at times be even more severe than the difficulties arising from the symptoms of the disease itself.

Stigma can also have a negative impact in terms of receiving and seeking social support. Goffman (1963) proposed that by avoiding feared discrimination and rejection, people with mental health difficulties may limit their social interaction to individuals who are also stigmatised or who are accepting of the diagnosis such as close family members. To test Goffman's theory, Link (1987) examined the correlation between withdrawal from social interaction due to concerns about stigma and reliance on individuals within households for emotional and practical support. As predicted, they found that withdrawal in response to concerns about stigma was positively associated with reliance on individuals within the household for support but were negatively associated with reliance on individuals outside the household. In other words, they concluded that people with mental health difficulties who avoided social interaction also tended to turn to members of their own family rather than to people outside the family for emotional and practical support.

Stigma has also been shown to negatively affect people's willingness to engage with mental health services (Holmes & River, 1998). In addition, Dinos (2004) reported that avoidance of help-seeking was one of the most common consequences of stigma experiences. In another study, Camp et al. (2002) examined the relationship between perceived stigma and discontinuation of therapy. His study revealed that that experiences of stigma in relation to psychiatric diagnosis predicted early treatment discontinuation in elderly patients with major depression.

As illustrated by the studies above, stigma and discrimination takes many forms from overt discrimination to subtle comments and self stigma. One question often raised in the literature is whether stigma applies to mental illness in general or differs by diagnosis. Empirical evidence on this issue is mixed. On one hand, research suggests that there is a nonspecific label effect, implying that people labelled mentally ill, regardless of the specific psychiatric diagnosis, are stigmatised more severely than those with other health conditions (Corrigan et al., 2000; Weiner, Magnusson, & Perry, 1988; Jones et al. 1984). On the other hand, some studies have suggested the public differs in terms of how much they discriminate based on the specific psychiatric diagnosis. For example, according to Pescosolido et al. (1999), people with psychotic disorders are judged more harshly than people with depression or anxiety disorders.

1.3.6. Stigma and Specific Diagnoses

Crisp et al (2000) carried out interviews with 1737 adults about their perception of people with mental health difficulties (such as severe depression, panic attacks, schizophrenia, dementia, eating disorders, alcoholism and drug addiction). They found that respondents commonly perceived people with schizophrenia, alcoholism and drug addiction as unpredictable and dangerous. In addition, participants generally perceived people with any of the seven disorders as difficult to talk to and 23% responded that people with depression could pull themselves together.

In the case of depression, Pyne et al. (2003) compared levels of perceived stigma in depressed and non-depressed individuals, and found that being in treatment for depression compared with never having experienced depression was associated with significantly higher levels of perceived stigma. In addition, the study revealed that greater depression severity and meeting criteria for current major depression were also significant predictors of perceived stigma. Roeloffs (2003) compared stigma associated with depression with stigma associated to other conditions such as HIV, diabetes and hypertension. They found that 67% of participants expected negative consequences due to disclosure of depression on gaining employment, 59% for obtaining health insurance, and 24% on friendships. They found that stigma associated with depression was greater than stigma associated with hypertension or diabetes, but less than that associated with HIV. In another study, Raguram et al. (1996) compared stigma related to depression with stigma related to somatisation. They found stigma scores to be positively related to depressive symptoms and negatively related to somatic symptoms. Their explanation for this was that although both depressive and somatic symptoms were distressing, depressive symptoms, unlike somatic symptoms, were seen as socially disadvantageous.

Another diagnosis that has attracted increasingly more attention in terms of its potentially stigmatising effects is Borderline Personality Disorder (BPD). One of the reasons for this is the increase in the number of people being given this diagnosis (Moran, 2002) and the stigma associated with it (Horn, 2007). There is also considerable debate in the literature about the validity of diagnosis, in part due to the heterogeneity amongst people who are diagnosed (Higgit & Fonagy, 1993). Dinos et al. (2004) carried out a qualitative study comparing overt and covert stigma across different psychiatric disorders including schizophrenia (N=13), bipolar affective disorder (N=5), dual diagnosis (N=13), major depression (N=5), mixed Anxiety and depression (N=6),

eating disorders (N=2) and personality disorders (N=2). They found that the service users with a diagnosis of personality disorder were often affected by patronising attitudes and feelings of stigma even if they had not experienced any overt discrimination. According to Watts and Morgan (1994), in addition to experiencing stigma from the general population, people diagnosed with borderline personality disorder may also encounter discrimination from mental health professionals. Watts and Morgan (1994) argue that because a diagnosis of borderline personality disorder carries with it particular negative connotations it may invite punitive as well as therapeutic responses from clinicians.

Research on the experience of stigma by those with a psychosis-related diagnosis indicate that they often face prejudice and discrimination from a range of different sources and that avoidance and withdrawal are amongst the most common coping strategies leading this group to be very vulnerable to social isolation and exclusion (Knight et al., 2003). Switaj et al. (2009) carried out a cross-sectional study looking at the extent and socio-demographic predictors of stigma experienced by service users with a diagnosis of schizophrenia. They found that experience of stigma was common in this population, exemplified by witnessing others saying offensive things about people with mental health difficulties, worrying about being viewed unfavourably and been treated as less competent. In addition, Dinos (2004) found that higher levels of stigma in people with a diagnosis of psychosis-related disorders were linked to lower subjective quality of life and younger age of illness onset. They also found that although stigma was a pervasive concern to almost all participants, people with a psychosis-related diagnosis were most likely to report feelings and experiences of covert stigma and were most affected by them. Finally, Dinos (2004) found that only participants with schizophrenia, bipolar affective disorder and drug addiction reported experiencing physical violence, verbal abuse and loss of contact with people because of their illness.

Few studies have been carried out on the experiencing of stigma in relation to receiving a diagnosis of bipolar disorder. Dinos' (2004) study included five participants with a diagnosis of bipolar but he does not summarise their experiences separately. Perlick (2001) found that concerns about stigma associated with mental illness reported by persons diagnosed as having bipolar affective disorder during an acute phase of their illness, adversely affected aspects of their social adaptation at follow-up. He noted that individuals who reported higher levels of concern about stigma at baseline had more

impaired social functioning in interactions with persons outside their family but not in interactions with family members.

1.4. Positive Experiences of having a Diagnosis

It is often assumed that being labelled with a psychiatric diagnosis only has negative consequences for oneself. However, results from studies looking at the impact of living with a diagnosis are sometimes either inconclusive or contradictory, suggesting that negative consequences may not always occur. Hayne (2003) found that a diagnosis had the potential to legitimise and acknowledge a person's difficult experiences and as such she argues that receiving a psychiatric diagnosis can help make illness more evident and treatment more possible. In addition, some regard the formulation and sharing of a psychiatric diagnosis as itself therapeutic, in that psychological symptoms can be given meaning and effectively discussed with the patient (e.g. Brody & Waters, 1980). Dinos et al. (2004) also pointed out some positive aspects of being given a diagnosis and noted that when participants accepted their diagnosis, they showed better adjustment. A number of participants in his study expressed relief at having been given a diagnosis and reported that living with a diagnosis did not prevent them from achieving things at a social or a personal level. Although stigma about mental illness was a pervasive and serious concern to most participants in his study, Dinos et al. (2004) concluded that diagnoses might be useful in providing both patients and families with the recognition that the array of symptoms experienced are 'real', and that may lead to treatment, adjustment and recovery.

1.5. Experience of Receiving a Psychiatric Diagnosis

Limited research has been carried out on the experience of receiving a psychiatric diagnosis. However, research on people's experience of receiving a medical diagnosis could provide some insight into key issues facing someone who has been diagnosed with a psychiatric diagnosis. Schrooten et al. (2001) studied 1366 people's experience of receiving a diagnosis of HIV. They found that participants did not feel comfortable with the way positive test results were given. According to Schrooten et al. (2001), over half of the respondents felt they did not receive adequate support when they were informed about being HIV positive, with 19% experiencing feelings of rejection. In another study by Baum & Mundy (2004), receiving a medical diagnosis was found to be linked to extreme fear, helplessness, or horror. Interestingly, in the field of medicine, receiving a medical diagnosis as a potential stressful and traumatic event has become a

particular focus for researchers but this has not yet been echoed within psychiatric research.

Some studies do report on the experience of receiving a psychiatric diagnosis. Hayne et al. (2003) carried out a thematic analysis on interviews of 14 people who had experienced receiving any psychiatric diagnosis. They found four main themes: 'A knowledge that knows', 'destructive (gift) of difference', 'making visible the invisible' and 'making knowledge knowledgeable'. Participants described both positive and negative aspects in relation to receiving a diagnosis. 'A knowledge that knows' described a sense that the diagnosis was experienced as knowledge that could not be challenged or disputed, causing distress and confusion in terms of understanding the self. 'Destructive (gift) of difference' illustrated how diagnosis was experienced both positively (by confirming and legitimising personal experiences) and negatively (by declaring personal experiences as illness). 'Making visible the invisible' reflected participants' experiences of healing gained from the diagnosis by gaining access to services and treatment. Finally, 'Knowledge made knowledgeable' represented the idea that diagnosis had the potential to make people feel more knowledgeable, providing a new lens for attaining a sense of enhanced 'self' and better informed as to ways which could lead to improved functionality.

Horn et al. (2007) conducted a qualitative study using Interpretative Phenomenological Analysis (IPA) on five service users' experiences and understanding of being given a diagnosis of BPD. They found that experiences could be categorised under the following themes: 'knowledge as power', 'uncertainty about what the diagnosis meant', 'diagnosis as rejection', 'diagnosis is about not fitting' and 'hope and possibility of change'. As in the study by Hayne et al (2003), they also found that participants identified both positive and negative aspects of receiving a diagnosis. Positively, participants described how a diagnosis provided a valuable framework for thinking about their difficulties. Participants also described a sense of relief and having their difficulties described in a way that made sense or fitted with their experiences. The findings also highlighted the positive function of diagnosis as providing access to services, support and therapy. Negatively, participants reported experiencing diagnosis as a rejection from services and also feeling that the label did not fit. Some participants experienced receiving the diagnosis as a negative judgement on them which lowered self-esteem or as having no meaning and not helping them understand their difficulties.

Findings suggested that participants in this study drew on personal relationships in order to find hope and meaning. Horn et al. (2007) conclude that the way in which diagnosis is imparted can have a negative impact on further engagement with mental health services, especially if the diagnosis is experienced as a rejection. They emphasise the importance for mental health workers to highlight the useful aspects of a diagnosis in discussions with service users. They recommend an environment of trust and acceptance is provided to have such discussion, using externalising and allowing service users to come up with their own descriptions of their difficulties. Due to the potential stigmatising effects of the BPD diagnosis, the authors also suggested employing a social constructivist perspective as an alternative to using the BPD diagnosis.

Pitt et al (2009) carried out IPA on interviews from eight people about the impact of having a diagnosis of psychosis. The study also revealed that diagnosis can involve both positive and negative aspects as illustrated by two dichotomies: 'Means of accesses vs. cause of disempowerment' and 'naming the problem' vs. 'labelling the person'. As in the studies described above, some participants in this study found that having a diagnosis of psychosis paved the way to getting access to treatment, support and understanding. In contrast it could be a cause of disempowerment. Some participants reported not being told of their diagnosis or not receiving enough information about it. Another source of disempowerment for some participants was an overreliance on the medical model and medication as the only option for treatment. In addition, where lack of information followed the diagnosis, participants tended to experience the process of receiving a diagnosis as labelling and stigmatising. In spite of this, some participants viewed the diagnosis as providing a helpful framework for understanding and explaining their symptoms and experiences, conceptualised as 'naming the problem'. Regardless of whether a diagnosis was experienced positively or negatively, it was found that all participants experienced diagnosis as a cause of social exclusion. Nevertheless, Pitt et al. (2009) reported that all participants were able to form new social networks and achieve valuable roles in society. Pitt et al. (2009) concluded that the way in which diagnosis is imparted could have an impact on the recovery process and social inclusion and highlighted the importance of imparting diagnosis with a sense of hope for recovery.

1.6. The role of the Client-Clinician Relationship in Receiving a Psychiatric Diagnosis

Another aspect that might be important in relation to receiving a diagnosis is the quality of the relationship and of the communication between the clinician and the client. The doctor-patient relationship (to be referred to as Client-Clinician relationship/communication) has been highlighted as an important factor in achieving and maintaining treatment satisfaction and adherence (Cruz, 2002). However few studies have explicitly researched the role of the client-clinician relationship when receiving a psychiatric diagnosis.

1.7. Rationale and Aims

This section outlines the rationale for the present study by illustrating how it fills an important gap in the literature. In addition, a rationale for the sample frame is also provided in relation to choosing to focus specifically on bipolar disorder and restricting the sample to only include recently diagnosed individuals. Finally, the section provides a rationale for choosing IPA as the method of choice and an outline of the overall and specific aims of the study.

Diagnosis has been a fundamental part of psychiatric assessment and treatment for many years. While most research about being diagnosed have focused on the long-term negative effects of having a diagnosis, such as stigma (Hayward and Bright, 1997), some research has also shown that diagnosis can pave the way to accessing services and getting support (Hayne (2003). Little is known about why some people adjust better than others, however recently it has been proposed that the way in which diagnosis is imparted may play a crucial part in the recovery process (Pitt et al., 2009). The experience of what it feels like to receive a psychiatric diagnosis is vastly under-researched and the few studies that have been carried out so far have focused on psychiatric diagnosis in general (Hayne et al., 2003), personality disorder (Horn et al., 2007), or psychosis (Pitt et al., 2009). While results from these studies indicate that there is a great deal of overlap between experiences of receiving different diagnoses, such as the function of diagnosis as providing a valuable framework for understanding and explaining experiences, it is also evident that each diagnosis brings about a particular set of concerns for the people who receive them. For example, Horn et al. (2007) reported that participants who received a diagnosis of BPD sometimes experienced the diagnosis as a rejection from services, but this theme is not echoed in the studies by

Hayne et al. (2003) or Pitt et al. (2009). With this in mind we wanted to focus specifically on *one* diagnosis. The main reason for choosing bi-polar disorder was that so far no studies have been identified with a specific focus on the experience of receiving this particular diagnosis. This study therefore fills an important gap in the literature and the aim was to enable us to highlight some of the similarities and differences between the findings from the studies mentioned above and the findings from the present study in relation to helpful and less helpful aspects of receiving the diagnosis.

In addition to focusing specifically on bipolar disorder, other parameters were also set in relation to the sample frame for this study. As such, only service users between the age of eighteen and sixty four who had received a diagnosis of bi-polar disorder within the last year were interviewed. The reason for excluding older adults was mainly pragmatic rather than theoretical, as the services who had agreed to assist in the recruitment process only served service users between the age of 18 and 64. The decision to focus specifically on service users who were recently diagnosed (within the last year) was mainly due to the specificity of the research question, namely the experience of receiving their diagnosis. As this research did not focus on the long-term effects of having a psychiatric diagnosis or what difficulties have led to getting such a diagnosis (for which a broader sampling frame would have been appropriate) but rather this research focused specifically on the experience of what it feels like to have one's difficulties described in terms of a psychiatric diagnosis. As such, we believe the aims of this research project would be best served by interviewing service users who had recently received their diagnosis as these service users would be in a better position to give a more accurate and more detailed account of their experiences.

As mentioned, the main aim of this research project was to explore Service Users' experience of receiving a diagnosis of Bi-polar disorder. Ultimately we wanted to raise awareness of the helpful and less helpful aspects of this process, to assist clinicians who are imparting diagnosis in doing so and to ultimately improve the experience of receiving a diagnosis of bipolar disorder for service users by reducing stigma which according to Knight et al (2003), Dinos (2004) and Byrne (2000) may play a role in relapse prevention and aid the recovery process.

Specific areas of interest were:

- a. How Service Users' make sense of their experience of receiving a diagnosis of bipolar disorder.
- b. Service Users' understanding of their diagnosis.
- c. If the diagnosis fitted with the Service User's own understanding of their difficulties.
- d. Service User's perceived consequences of having a diagnosis of Bi-polar.

The chosen method of analysis was Interpretative Phenomenological Analysis. In deciding upon which method was best suited to answer the research questions, several considerations were made in relation to the aims of the research and the sample frame. The aim of this study was to explore the way service users make sense of their own experiences. IPA was seen as being consistent with this aim. In addition, IPA's focus on phenomenology offers a flexible approach to research which allows participants to take an active role in shaping the direction of the research. In this way, IPA is ideal for examining unexplored topics such as the one under investigation. Furthermore, the utility of IPA has already been shown in relation to service users' experience of having a diagnosis of schizophrenia (Pitt et al., 2009) and personality disorder (Horn et al., 2007). Finally the relatively homogenous sample in relation to a number of key variables (diagnoses, age, functioning), is in keeping with IPA's requirements as recommended by Smith et al. (2009).

2. Methods

The method section outlines the rationale for choosing a qualitative paradigm and for selecting Interpretative Phenomenological Analysis (IPA) as a method of enquiry. It further provides a detailed description of the data collection and data analysis procedures. The analytical process is further illustrated by the Audit Trail provided in Appendix 7.

2.1. Choosing a Qualitative as opposed to Quantitative Methodology.

The topic of psychiatric diagnosis produces a multitude of reactions and opinions from service users and clinicians alike (Van Os, 2010; Frese, 2010; Vonnegut, 2010; Horn et

al., 2007; Rose and Thornicroft, 2010; Pitt et al., 2009; Hayne et al., 2003). As mentioned previously, this area is both complex and under-researched and no studies have been identified looking specifically at the experience of receiving a diagnosis of bipolar disorder. Such requirements for exploration, clarification and discovery does not lend itself to the use of quantitative, deductive methods set within a positivist paradigm, which apply reductionist testing to a defined phenomenon in a controlled environment. In order to capture the complexity of this topic and to allow the possibility for new knowledge to emerge, using a more flexible and less restrictive methodology that would take into account the wider context was deemed more appropriate for the current investigation. Such methods can be found within the interpretative and phenomenological paradigm. Methods within this paradigm take a relative stance to knowledge and support the belief that reality is constructed by subjective perception and opinion. This tradition offers a range of methods for conducting research that aims to support discovery of phenomena through interpretation and personal construction using induction and reflectivity.

2.2. Design.

This study utilized a cross sectional qualitative research design. A purposive sample of nine service users was used, in keeping with IPA requirements to have a small and fairly homogenous sample. Semi-structured interviews were carried out and transcripts were analysed using IPA (Smith & Osborn, 2003; Smith, 2007; Smith et al. 2009).

2.3. Methods for Data Collection.

This section describes the development of the semi-structured interview schedule used in this study along with an outline of the recruitment, interview and transcription procedure.

2.3.1. Choosing Semi-Structured Interviews as a Mode Enquiry

Semi-structured interviews are one of the most common forms of data collection procedures in qualitative research. Lofland and Lofland (1984) described an interview as a directed conversation that allows a detailed exploration of a particular topic with a person who has had the relevant experiences. The advantage of semi-structured interviews over other forms of data collection (such as structured interviews and surveys) is that it provides a more flexible approach to data collection which allows participants to talk about aspects that are important to them while at the same time

allowing the researcher to follow particular interesting aspects as they emerge during the interviews (Smith, 1995). According to Smith (1995), semi-structured interviews are particularly indicated where one is interested in complexity and in process or where an issue is controversial, personal or unexplored. As such, the semi-structured interview schedule serves as a flexible guide and participants have some influence over the direction of the interview. In short, the semi-structured interview was chosen as the method for data collection for this study as it tends to produce richer data than a structured interview, as it facilitates rapport and empathy with the participant, as it allows a greater flexibility of coverage and enables the interview to enter into novel areas.

2.3.2. The Semi-Structured Interview Schedule.

A semi-structured interview schedule (Appendix 5) was developed based on several sources of information: relevant findings in the literature (Hayne et al., 2003; Horn et al., 2007; Pitt et al., 2009), discussions with supervisors, and published guidelines on devising interview schedules (Smith & Osborn, 2003; Smith, 2007; Smith 2009; Charmaz, 2006). The schedule was used flexibly, in order to allow unanticipated areas to emerge.

The overall aim of the interview was to elicit information from participants in relation to their experience of receiving a diagnosis of bipolar disorder. The main areas of interest were: a. Participants' understanding of the diagnosis they had been given, b. Whether or not they felt that the diagnosis accurately described their current symptoms or had changed their understanding of their difficulties, and c. Participants' beliefs about the impact their diagnosis might have on their future care and their life in general. These broad themes had emerged from findings within physical health settings (i.e. Schrooten et al., 2001) and research examining service users' experience of the long-term impact of living with a psychiatric diagnosis such as Hayne (2003), Pitt et al (2009) and Horn et al. (2007).

In devising the semi-structured interview schedule guidelines from Smith (1995), Smith and Osborn (2003) and Charmaz (2006) were followed. Smith (1995) has identified a number of key stages in producing an interview schedule. First, an overall topic should be decided upon, and then followed by relevant areas within the topic. These areas should then be sequenced in a logical and appropriate way. For example, in this

interview schedule, questions about particular sensitive areas (such as stigma and impact on the future) were asked towards the end of the interview when participants were likely to feel more relaxed and comfortable. According to Smith (1996), specific questions and prompts should be developed relating to each area of interest. In addition, questions were designed to be as neutral and non-leading as possible and jargon was avoided to increase comprehensibility. Questions were also designed to be open, thus avoiding yes/no responses where possible and encouraging participants to talk openly about the topic as possible. An example of an open question from the interview schedule was 'Could you tell me about your experience of speaking to a psychiatrist? Furthermore, general questions were asked in the beginning to allow the participant to talk about what was important for them in relation to the specific issue. This was followed by specific prompts where necessary. Initial interviews were used to refine the interview schedule by identifying unexpected areas of interest in the transcripts and by asking participants if they felt that there was anything that had not been covered by using the original draft. In this way, participants were able to take an active part in shaping the direction of the research and as such confirms this research as situated within a social constructionist framework. This resulted in a final draft of the interview schedule, which included questions about current mental state, mental state at time of receiving diagnosis and reason for seeking help.

One aim of the interviews was to allow participants to feel more able to expand on their own ideas, thus balancing the power relations between the researcher and the participant and democratising the research process. Using a semi-structured interview schedule therefore helped the researcher to interact with the participants in a sensitive way and made it possible to create an environment where ethical issues were kept at the forefront of the research process. In addition to using a flexible approach which allowed participants to steer the direction of the interviews, at the end of each interview participants were also asked specifically if they felt that there were any areas that had not been covered by the interview which they felt were important. These areas were then expanded on and including in the interview schedule for the following interview. In this way, service users were not only able to influence the direction of their own interview but also subsequent interviews. In this research project, the interview schedule was based on previous research findings and discussion with experienced supervisors. One area where service user involvement could have been improved was in the development of the initial interview schedule. If I was do carry out a similar study in the

future, I would hold a service user consultation group to assist in developing the interview schedule before starting the research. If I had involved service users at this stage, this would undoubtedly have shaped the interview schedule, perhaps making questions more pertinent and relevant in relation to the topic under investigation and ultimately affected the results and increased face validity.

2.3.3. Sampling Frame (Inclusion and Exclusion Criteria)

The sampling in this study resembled a purposive sampling, as participants were selected on having had certain desired experiences such as having received a diagnosis of bipolar disorder within the last year. This is in keeping with IPA requirements to have a fairly homogenous sample. In addition, participants had to be aged between 18 and 64 and have a good enough command of the English language to be able to take part in an interview and reflect on their experiences. The reason for excluding older adults was mainly a pragmatic rather than a theoretical one as the services who had agreed to assist in the recruitment process only served service users between the age of 18 and 64. Excluding a group of people based on pragmatic reasons may have implications for the generalisability of the results of the study and as such caution should be taken when applying the findings to an older adult population. Finally, service users who were deemed ‘at risk’ by their psychiatrist were not invited to take part in this study.

2.3.4. Participants.

Table 1 presents the external characteristics of the nine participants who took part in this study. The sample consisted of seven women and two men. All participants were diagnosed with bipolar disorder within the last year. The time since diagnosis ranged from one to 47 weeks with an average time since diagnosis of 17 weeks. The age of participants ranged from 26 to 45 with a mean age of 38.3. Three participants had received a diagnosis of bipolar 1, five had received a bipolar 2 diagnosis (Two of which were rapid cycling) and one participant had received a diagnosis of bipolar other (rapid cycling). Seven participants identified themselves as White British, one as Black British and one as African. Two participants were unemployed and seven were in full-time employment. Eight participants were on medication, two participants were receiving psychological therapy, while one was waiting to start therapy.

Table 1: Demographic Information about Participants

Participant Number	Gender	Ethnic Background	Age	Occupation	Diagnosis	Time Since Diagnosis*	Therapy	Medication
1	Female	Black British	33	unemployed	Bipolar 2	1	No	No
2	Female	White British	26	Teacher	Bipolar 2	16	Yes	Yes
3	Female	White British	42	Self Employed	Bipolar 2	5	Yes	Yes
4	Female	White British	40	Pharmacy Technician	Bipolar 1	40	No	Yes
5	Male	White British	42	Nurse	Bipolar other	34	No	Yes
6	Female	White British	45	unemployed	Bipolar 1	8	No	Yes
7	Female	African	41	Waitress	Bipolar 1	47	No	Yes
8	Female	White British	43	Carer	Bipolar 2	4	No	Yes
9	Male	White British	33	Graphic Designer	Bipolar 2	1	Referred	Yes

*Time since diagnosis is measured in weeks.

2.3.5. Procedure for Data Collection (Recruitment and Interviews)

Participants were recruited through Community Mental Health Teams (CMHTs) in South London and Maudsley (SLaM) NHS foundation trust. The study was presented to mental health professional in four CMHT's in SLaM. The teams were provided with copies of the inclusion and exclusion criteria and a summary of the study. Participants who matched the inclusion criteria were first approached by a member of their mental health team and providing them giving consent, contact details were passed on to the researcher who then contacted the participants regarding taking part in the study. Participants who agreed to be contacted were asked if they wanted further information and a meeting was set up with participants who expressed an interest in taking part. Upon meeting participants for the first time, they were given an information sheet (Appendix 2) outlining the study in detail. If agreeing to take part, participants were asked to sign a consent form (Appendix 3) and fill in an interview documentation sheet (Appendix 4) containing demographic questions.

Participants were given the opportunity to be interviewed, either on university or NHS premises or in their own home. Four interviews were conducted on King's College London (KCL) premises, three on NHS premises and two participants chose to be interviewed in their own home. The interviews lasted between 22 and 49 minutes and were recorded using a dictaphone. The interview schedule was rehearsed in advance but

used as a guide only, allowing participants to take an active part in shaping the direction of the interview. Often, the interviews did not follow the sequence of the interview schedule. At times questions were introduced earlier than they appeared on the interview schedule because it followed on from what the participant had just said. Some interviews did move away from the schedule to some extent and this was generally allowed as, according to Charmaz (2006), allowing the participants to talk freely can lead to novel discoveries. If participants had difficulty generating responses from the general questions, prompts were used to help with this. As recommended by Charmaz (2006), funneling techniques were used, where initial questions focus on general views and experiences and subsequent questions and prompts seek to elicit specific information. In addition, in order to maximize the amount of relevant information obtained, some questions were repeated and paraphrasing and clarification were used to make the participant feel heard and to reduce risk of misunderstandings. After the interview, each participant was offered psycho-education and/or sign-posting where necessary. Finally, participants were asked if they wanted a chance to comment on preliminary results and if they wanted a summary of the final results.

From the interviews, written verbatim transcripts were produced. Five interviews were transcribed by the main researcher and four were transcribed using a professional transcription service. A common aim of qualitative research is to provide an in depth understanding of an unexplored area. The often smaller sample sizes and the richness of data in qualitative research allow the researcher to immerse themselves in the data. According to Flick (2005) transcribing the interviews is an important aspect of this process as it increases familiarity with the transcripts and because ideas already start to develop about the data at this stage. For this reason, the majority of transcripts were transcribed by the main researcher but, due to time pressure, four interviews were transcribed using a professional transcription service with experience of transcribing for research purposes. As a result of this, it is possible that there was less familiarity with these four transcripts and that the analysis of them is slightly less rigorous. In the future I would aim to transcribe all interviews myself to increase familiarity with each interview as much as possible and improve rigour. In part, to compensate for this shortcoming, efforts were made to ensure as much familiarity as possible with each transcript. As such, all transcripts were listened to at least once and read through several times by the main researcher. In addition, each transcript was analysed in its own right as opposed to building on themes from previous transcripts and no computer

programmes were used to facilitate a personal involvement with all transcripts. To further ensure rigour, visual diagramming was also used, which involved cutting out pieces of paper with all relevant verbatim quotes from every single interview and placing them on a large table and repositioning them to reflect hierarchical relationships and relationships to other themes.

2.4. Methods for Data Analysis (Interpretative Phenomenological Analysis)

This section provides a rationale for choosing IPA and a detailed description of each step in the analytic process that led to the final set of master themes. A brief overview of the history of IPA and its recent developments are also provided. The interviews in this study were analysed using Smith and Osborn (2003), Smith (2007) and Smith's (2009) approach to IPA.

2.4.1. Background and Methodology behind IPA.

Interpretative Phenomenological Analysis (IPA) was introduced by Jonathan Smith in 1996 as an alternative to other established qualitative methodologies (such as Grounded Theory (GT), Discourse Analysis (DA) and Narrative Analysis (NA)). IPA is concerned with exploring and understanding the lived experience of a specific phenomenon and specifically the meaning that people attach to their experiences (Smith, 2004). IPA is theoretically rooted in critical realism (Bhaskar, 1978) and the social cognition paradigm (Fiske and Taylor, 1991). Critical realism purports that there are stable and enduring features of reality that exist independently of human conceptualisation and that differences in the meanings individuals attach to experiences are considered possible because they experience different parts of reality. The social cognition paradigm is founded on the premise that human speech and behaviour reflects these differences in meaning either directly or indirectly. Thus the key aim of IPA is to explore the (hidden) meaning behind people's subjective experiences. The key concepts and theoretical underpinnings of IPA are ideography, phenomenology and hermeneutics (Smith, 2004, 2007).

Ideography in IPA refers to the emphasis on the distinct experiences of particular people and the particular contexts in which those experiences occur (Smith, Flowers and Larkin, 2009). During the data analysis in this study, ideography was exemplified through attempting to understand each individual's experience before moving on to look at communalities and differences between individual accounts.

Phenomenology is the study of the structure of subjective experience and consciousness. It originated with Husserl who believed that the essence of true meaning could be understood through the use of intuition, which is uncontaminated by an individual's past experiences and viewpoints. This view has inspired much recent research in healthcare where the aim has been to explore individual 'lived experiences'. Traditionally, researchers carrying out phenomenology studies have aimed to 'bracket out' their own preconceptions (Colaizzi, 1978; Moustakas, 1994) using formal reflexive techniques (Heron, 1990; Duck, 1992). IPA differs from this position by stressing that, although the purpose of IPA is to attempt as far as possible to gain 'an insider perspective' of the phenomenon being studied, the researcher is central as an analytical instrument (Smith et al., 1999). As such, the researcher's beliefs are not seen as biases to be eliminated but rather as being necessary for making sense of the experiences the participants. The emphasis on the researcher's central role in meaning-making is what makes interpretation and hermeneutics a core component of IPA.

Hermeneutics is defined as the theory and practice of the interpretation of the meaning of texts (Elliott, Fischer & Rennie, 1999). The interpretative orientation of IPA draws on the theoretical perspectives of hermeneutic theorists such as Heidegger (Smith, 2007). Heidegger combined his view of phenomenology with theories of hermeneutics. His position was that human existence is bound up in the world and as such it is impossible for anyone (both researchers and participants) to disconnect from the context they find themselves in and reveal the fundamental truth about lived experience (Larkin, Watts and Clifton, 2006). In addition to this relativist stance towards knowledge, IPA has also been described as employing what is known as a 'double hermeneutic' in which the researcher is trying to make sense of the participant trying to make sense of their experiences (Smith & Osborn, 2003; Smith et al. 2009). To illustrate to connection between interpretation and phenomenology in IPA, Smith et al. (2009) point out that "Without the phenomenology, there would be nothing to interpret, without the hermeneutics, the phenomenon would not be seen."

2.4.2. Selecting the IPA Method

This section provides a rationale for selecting IPA. The aim of this study was to explore the way service users make sense of their own experiences of receiving a diagnosis of bipolar disorder. IPA was seen as being consistent with this aim, in that it is committed

to the examination of how people make sense of their experiences (Smith et al. 2009). IPA's focus on phenomenology and what Conrad (1987) calls 'taking an insider's perspective', allows the participant to play an active role in shaping the direction of the research. In this way, IPA offers an approach to research that is flexible, thus ideal for examining unexplored areas such as the experiences of receiving a diagnosis of bipolar. Furthermore, the utility of IPA has already been shown in relation to service users' experience of having a diagnosis of schizophrenia (Pitt et al., 2009) and personality disorder (Horn et al., 2007).

In selecting the method for analysis, other qualitative approaches were also considered. IPA was chosen over Grounded Theory (GT) as GT may be considered more of a sociological approach (Willig, 2001), which draws on comparisons within a larger sample in order to build theory. IPA by contrast can be seen as more psychological in that it gives a more detailed and nuanced account of the personal experiences of a smaller sample, more homogenous sample (Smith et al. 2009). As such IPA was seen as more in line with the aims of this study. A sample of nine might also have been considered too small for Grounded Theory. In addition, the flexibility offered by IPA in terms of allowing the analysis to move between individual and group experiences, made this an ideal approach for studying an unexplored area. Another approach which was considered was Narrative Analysis. Like IPA, Narrative Analysis does not require big sample sizes and can also be considered to be a social constructionist approach concerned with meaning-making. However, narratives are only *one* way of making sense of experiences and as such IPA was considered to be more flexible in that it could consider participants narratives as a way of making sense of experiences without being constrained by them (Smith et al. 2009). Finally, Discourse Analysis (DA) was considered but again it was felt that IPA was more in line with the aims of the study. A key distinction between IPA and DA is that DA examines the role of language in shaping a person's experience while IPA explores how people ascribe meaning to their experiences in their interactions with the environment (Smith, Jarman and Osborn, 1999).

2.4.3. Procedure for Carrying out IPA

The analysis was based on guidelines on IPA from Smith & Osborn (2003), Smith (2007) and Smith et al. (2009). The analytic process was also informed by guidelines for ensuring quality in qualitative research (Morse et al., 2002). The following sections

outline each phase of the analysis. For further illustration of the analytic process, please refer to the audit trail (Appendix 7).

2.4.3.1. Individual Case Analysis

In accordance with IPA's commitment to ideography, each interview was analysed in-depth in turn (Smith et al. 2009). In order to become familiar with each account and to get an overall sense of the data, each recording was listened to at least once, and the transcripts were read a number of times. Initial annotations were then made in the left margin of the transcript noting anything that was interesting and significant about what the respondent has said. This stage of the analysis was close to being free text analysis as recommended by Smith et al. (2009). Some comments illustrated attempts to summarise or paraphrase while others were more exploratory and conceptual in nature. As the analysis progressed through each transcript, attention was paid to similarities or contradictions in what was said in the account. Following the initial annotations, the transcript was re-read and the right margin was used to note emergent themes, drawing on both the transcript itself and on the annotation from the left margin. Here the initial notes from the left margin were transformed into succinct phrases which aimed to capture the essential quality of what was found in the text. Developing themes involved moving the response to a higher level of abstraction while at the same time maintaining the link back to what the participant had actually said.

2.4.3.2. Clustering of Emerging Themes

The next stage involved grouping together themes within each interview. Emergent themes were first listed chronologically and then moved around to form clusters of related themes. The process of grouping themes together in a meaningful way involved looking for verbatim evidence of connections between themes. This involved an iterative process of moving backwards and forwards between themes and transcript, making sure the clustering of themes were supported by the actual words of the participant. To aid the process of clustering, quotes and phrases from the participants were printed out and laid on a table in the clusters they belonged to. This facilitated building a hierarchical relationship between themes, developing sub-themes and Super-ordinate themes. Developing themes and super-ordinate themes involved looking at similarities and differences between sub-themes. It also involved considering the context in which certain themes emerged, the function of the theme and looking for the frequency with which a theme is supported. To further assist the process of developing

super-ordinate themes, memos were written outlining the analytical decisions. Each interview was analysed in this way until themes had been developed and clustered from all nine interviews. An example of this was the development of the theme ‘Diagnosis as legitimising’. Initially, the use of diagnosis to explain behaviours to others and to understand oneself were separate themes. However at a higher level of abstraction, what binds these two sub-themes together to form the main theme is the use of diagnosis to legitimise distress both internally and externally.

2.4.3.3. Cross-Case Analysis and Master Themes

The next stage involved looking for patterns across cases. The aim at this stage was to develop themes which were abstract enough to capture a shared experience among participants while at the same time remaining grounded in the ideography of the individual’s experience. The themes were not selected purely on the basis of their prevalence within the data but also on the richness of particular passages that helped to highlight and enrich the conceptualisation of the experience of receiving a diagnosis of bipolar disorder. This involved making lists of sub-themes and super-ordinate themes for the group as a whole, developing master themes which represented shared higher-order experiences. An example of cross case analysis was the formation of the Diagnosis as Cause of Empowerment. Not all participants experienced empowerment in the same way. For some, empowerment was experienced as an internal sense of agency and of beginning to gain some control over their symptoms. For others, empowerment came through the contact with services and the feeling of hope and containment this brought with it. Through cross-case analysis, it was possible to link these individual experiences together to form the final master themes.

2.4.3.4. Reporting the Results

This stage involved translating the themes into a narrative account through explaining and illustrating themes. The narrative was based on the table of master themes and supported by the use of verbatim extracts from the transcripts. In doing so, a clear distinction can be made between what the participants actually said and how the researcher made sense of what the participant said.

2.4.4. Memos and Diagrams

Memos were written about emerging themes and their relationships, reflecting what is being noted about the data and were also used to describe how themes were refined and repositioned. In addition to memos an audit trail of the clustering of themes from each interview was kept as a way of keeping track of emerging themes and how themes related to each other. As the analysis progressed there was also a need to visually plot out and view the progress of the analysis by drawing the conceptual relationships on paper. Diagrams were used in order to illustrate how Themes and sub-themes were linked together and helped depict the dimensions of all the master themes.

2.4.5. Saturation and Sample Size

Adequate sample size in qualitative research is relative. According to Smith et al. (2009) there is no right or wrong sample size when using IPA as the primary concern is with the detailed account of individual experiences. However, Smith et al. (2009) provides a rough guideline for sample sizes when using IPA and suggest that three to six participants would constitute a reasonable sample size for undergraduate and master's projects and between four to ten for professional doctorates. In line with Smith et al. (2009), Sandelowski (1995) argues that deciding on a sample size is not about judging if a sample is large or small, but rather whether it is too large or too small for the intended purposes of the given study.

Another standpoint is proposed by Charmaz (2006). According to her, sample size in qualitative research should be guided by the principles of saturation. Saturation as a concept was initially associated with grounded theory but has since been used as a measure to determine sample size in qualitative research in general. Glaser & Strauss (1967) and Strauss & Corbin (1998) provide the following description of saturation. According to them, saturation occurs when: 1) further interviews do not add new data or relevant data regarding an existing category, 2) Each category is well developed in terms of its properties and dimensions, demonstrating variation, and 3) the relationships among categories are well established.

Whereas the definition of saturation is clear, little guidance is available as to how one would establish if saturation had been reached in a specific sample. In an attempt to determine the level of saturation in the present study, I followed an example provided by Guest et al. (2006). They carried out a systematic analysis of their own data from a

study of sixty women, involving reproductive health care in Africa. They examined the codes developed from their sixty interviews, in an attempt to assess at which point their data were returning no new codes, and were therefore saturated. Their findings suggested that data saturation had occurred at a very early stage. Of the 36 codes developed for their study, 34 were developed from their first six interviews, and 35 were developed after 12 interviews. Their conclusion was that for studies with a high level of homogeneity among the population, a sample of six interviews may be sufficient to enable a development of meaningful themes and useful interpretations.

From the nine interviews in the present study, 26 separate codes relating to the topic under investigation were identified. Of these codes, 20 had emerged after the fifth interview and after the fifth interview, further interviews only produced two additional codes. Furthermore, these additional codes were not indicative of the presence of new themes but rather representing further variability within established themes and sub-themes. While it is possible that carrying out more than nine interviews would have revealed additional codes representing further variability within the identified themes and sub-themes, I would argue that it is unlikely that additional interviews would have led to the emergence of new themes or master themes. In addressing the question of whether or not saturation was reached in this study, I would argue that the master themes, themes and sub-themes presented are representative of the main issues relating to the experience of receiving a diagnosis of bipolar disorder for this particular population. As such, I feel that I have satisfied Glaser & Strauss' (1967) first point, that further interviews would not have added any further significant data. I would also argue that the three master themes are well developed and demonstrate sufficient variability to make meaningful comments and interpretations about the topic under investigation. However, as mentioned, it is possible that further interviews would have revealed further variability within themes and also illustrated more clearly how categories relate to each other. In conclusion, based on the considerations mentioned above, I decided to stop recruiting after the ninth interview as I felt that the data was rich enough to comprehensively illustrate the complexity of the experience of receiving a diagnosis of Bipolar Disorder and to satisfactorily answer the research questions.

2.5. Quality Assurance

Qualitative approaches in general do not assume that there is *one* correct or truthful reading of a text and IPA in particular is inherently subjective because of the central position of the researcher as the instrument for the analysis. Therefore, assessing the quality of qualitative research requires different criteria than those used in assessing the validity and reliability of quantitative studies. In order to ensure the quality and rigour of the findings from this study, guidelines by Elliott et al (1999) were adhered to. Elliott et al. (1999) propose the following guidelines for publishing qualitative research: a. Reflexivity and owning one's perspective, b. Situating the sample, c. Grounding in examples, d. Providing credibility checks, e. Coherence, f. Clarifying the scope of the research (general vs. Specific) and g. Resonating with the reader. Each of these points will be considered in turn below in terms of how they relate to the present study.

a. Reflexivity and owning one's perspective:

Reflexivity is a central component of qualitative analysis. It can be thought of as the ability to position oneself in relation to the enquiry and to reflect on and consider the dynamics between researcher and data (Finlay and Gough, 2003). As Biggerstaff and Thomson (2008) point out, there is an apparent paradox when using reflexivity with IPA as IPA emphasises putting the researcher at the centre of the analysis. However, IPA purports that there is no such thing as a view from nowhere (Biggerstaff and Thomson, 2008), so rather than attempting to bracket out the subjectivity of the researcher, IPA moves in the opposite direction by acknowledging the researcher's role as central to analytic process. The following section therefore comprises a personal statement attempting to make my position in relation to the topic explicit and to, as Elliott et al. (1999) put it: 'own one's perspective'.

I am a thirty-six year old white Danish man. I was born in a 'middle class' suburb to Aarhus (Denmark's second largest city) where I lived until moving to London in 2001. I am gay and currently living with my partner and two adopted children. I did a BSc in Psychology and an MSc in Psychological Research Methods at the University of Westminster in London. I have worked in the field of mental health for the last four years and I am currently a Trainee Clinical Psychologist in my final year of training at the Institute of Psychiatry where I am undertaking a specialist psychotherapy placement at the Maudsley Psychotherapy Service.

In terms of theoretical orientation I would describe myself as integrative and acknowledge the influence of a wide range of therapeutic modalities on my clinical practice. In terms of epistemology, I would position myself somewhere between positivism and relativism. Throughout my training I have become increasingly more influenced by social constructionist approaches and in general I see mental health difficulties as existing on a continuum. I believe that they are concrete phenomena that people experience but that these experiences may vary from person to person given the individual's personal life experiences and circumstances. My interest in the present topic stems from my own experiences of being diagnosed with depression when I was younger. In my clinical practice, I view diagnosis as a useful framework for thinking about interventions but would only use such terms if in agreement with the client.

b. Situating the sample:

In order to allow judgements to be made about the range of people these findings might be most relevant to, Elliott (1999) recommend that basic descriptive data should be provided about the sample. In this study each participants were asked to fill out a participant information sheet and the following demographic information was collected in order to situate the sample: age, gender, ethnicity, occupation, diagnosis, time since diagnosis and whether or not participants were in therapy and/or taking medication. Please see section 2.3.4. for a presentation of the external characteristics of the sample in this study.

c. Grounding in examples:

In order to allow an external appraisal of the fit between the data and the researcher's understanding of the data, Elliott (1999) recommend that examples from the transcripts are used to illustrate the point that the researcher is trying to make. To adhere to this principle, verbatim quotes were used to illustrate the properties of all the themes presented in this report. In addition, a clear distinction has been made between verbatim quotes and the researcher's interpretation of these quotes by reporting all quotes in italics, by using quotation marks and by clearly referencing which transcripts the quotes were taken from.

d. Providing credibility checks:

One way of establishing credibility in qualitative research is, according to Elliott (1999) by receiving feedback on the findings from the original informants (i.e. the

participants). In this study, all participants were invited to provide feedback on the findings. This included asking questions such as ‘Does the themes make sense?’, ‘Does the themes reflect your experience?’, and ‘Is there anything important that is not included in the themes?’ One participant opted to participate in this part of the research process. Feedback from this participant was broadly in support of the findings and where feedback differed with the researcher’s interpretations, the data was re-visited and adjusted where appropriate (please see result section, discussion and section below entitled ‘resonating with the reader’ for further information about participants’ feedback).

Elliott (1999) also recommends using additional qualitative analysts as part of the analytical process in order to enable a review of the consistency, discrepancies, overstatements or errors in the coding. Credibility of the codes and emerging themes was assessed by inviting an independent researcher to read through *one* transcript and analyse it using the guidelines outlined above. The analysis from the independent researcher was then compared and contrasted with the analysis identified by the main researcher. When comparing the findings, there were many similarities between the codes and initial themes that emerged from my analysis and those that emerged from the analysis of the external researcher. For example, the external researcher also identified themes around the process of establishing fit between diagnosis and personal experiences and also highlighted the importance of diagnosis as an explanatory framework. One of the differences in relation to this theme was that in my analysis I had focused more on the importance of the process of establishing fit in terms of moving towards an acceptance of the diagnosis, whereas the external researcher’s emphasis was more on the potential power of the diagnosis to change participants’ understanding of themselves. It is possible that this reflects a difference in the researchers’ perception of the degree to which participants’ viewed receiving a diagnosis as something that could not be disputed or something that occurred through a process of interaction and negotiation between the service user and the diagnosing clinician. My sense was that many participants viewed their difficulties as not being categorically different from difficulties experienced in the general population and that receiving a diagnosis was one way of viewing their difficulties but not necessarily a more accurate way.

There were also many similarities in relation to the themes concerning stigma, discrimination and disclosure. As in my analysis, the external researcher highlighted

both perceived and actual stigma along with societal and self-stigma as present in the transcript. However, there were some differences between my findings and that of the external researcher in terms of the impact of stigma-experiences. In my analysis, I emphasise the role of stigma in relation to disclosure whereas the external researcher emphasised the role of stigma in relation to help-seeking. Help-seeking did feature in my analysis but as a separate theme in relation to empowerment and disempowerment. Another difference was that the external researcher had identified a single theme entitled: 'positive aspects of diagnosis', which encompassed aspects of establishing fit, enabling an externalisation of symptoms to reduce stigma and feeling empowered. All of these themes feature in my analysis but in separate themes. Similarly, the external researcher identified a separate theme about positive and negative aspects of the therapeutic relationship while aspects of these experiences in my analysis, figure as part of the themes regarding 'establishing fit' and 'searching for solutions.'

In conclusion, many similarities existed between my analysis and that of the external researcher. The main difference was in the structure of the themes and in the emphasis of specific aspects of the themes. While there were many similarities, the external researcher had identified a number of themes that were not included in my analysis. For example the external researcher had themes around reasons for help seeking and about the importance of social support. These themes were not included in my analysis as it did not relate to the specific aims of the research, which were to explore how it feels to receive a diagnosis. As a use of the external researcher as a measure of inter-rater reliability, my view is that there were many overlaps and similarities, which support good inter-rater reliability. However, a further use of an external researcher is to shape further data collection and analysis. I did not invite the external researcher to analyse the transcript until after I had collected and analysed all my transcripts. This can be seen as a limitation, as the differences between our analyses could have influenced and possibly improved and enriched my analysis. The next time I carry out qualitative research, I would introduce this measure much earlier in the process to allow the findings from the independent researcher to influence subsequent analysis in addition to functioning as a measure of inter-rater reliability. Finally, in order to further facilitate transparency and allow others to evaluate the consistency within the analytic process and consider alternative interpretations, an audit trail, an example of a memo and an interview transcript is provided (Appendix 6).

e. Coherence:

Elliott (1999) recommends that the data is presented in a way in which it achieves coherence and integration while at the same time preserves the nuances in the data. As recommended by Elliott (1999), a brief summary of each master theme is provided to depict both its temporal-sequential relationship to other master themes and the internal logical-hierarchical relationship between the themes and sub-themes that constitute it. This was followed by an in-depth description of the specific properties of each theme and sub-theme.

f. Clarifying the scope of the research (General vs. Specific research task):

Elliott (1999) recommends clearly stating the objectives of the research and how the selected sample serves these objectives. In the aims section, a rationale for the study is provided with specific reference to the chosen sample and method. In this piece of research, efforts were made to keep the sample fairly homogenous as recommended by Smith et al. (2009) when using IPA. Efforts were also made to keep a narrow focus in relation to the research task. The research question was specifically designed to get an in-depth understanding of the experience of receiving a diagnosis of bipolar disorder as opposed to the experience of living with a diagnosis of bipolar disorder or what difficulties led participants to receiving a diagnosis. Different questions were asked to elicit information about the same topic from different angles and funnelling techniques were used to encourage participants to elaborate on their answers, resulting in rich and detailed data. In addition, clear reference is made to the characteristics of the participants and due to the narrow focus of this research, limitations in terms of the generalisability of the findings to other samples are highlighted.

g. Resonating with the reader:

Elliott (1999) proposes that discussion is had with a third party about whether or not the findings resonate with the reader. Findings were discussed in supervision and presented to members of the university teaching staff, fellow students, examiners and finally to the participant who opted to participate in this part of the research process. Generally, the responses were positive and feedback suggested that the themes made sense and resonated with the recipients. The main criticism of the initial report of the findings came from the participant and the examiners in the viva. The criticism focused on the use of three dichotomies to describe the overall findings and it was suggested that these were replaced with three master themes within which the complexity and diversity of

the participants' experiences were captured. This feedback was incorporated into the final reporting of the results.

2.6. Ethical Considerations

Ethical approval was obtained by NRES Committee London-Surrey Borders on 09/11/11 (Appendix 1).

2.6.1. Informed Consent

The purpose of the study was explained in detail to participants using the participant information sheet (Appendix 2) before they were asked for informed consent (Appendix 3). Participants were also informed that the interviews would be recorded and that if they for any reason wished to have the recording stopped, they should let the researcher know. In addition, participants were informed of their right to refuse to answer particular questions without having to give a reason for it and of their right to withdraw or have their data excluded from the study.

2.6.2. Confidentiality

It was assumed that talking openly about receiving a diagnosis of bipolar disorder might have been difficult for some people because of misconceptions in society. As a result, fears of breach of confidentiality could be high among some participants. This could result in some participants finding it difficult to talk about their experiences or wanting to conceal important aspects of their experiences. This runs counter to the goals of the research which aimed to discover the details of the participants' experiences and ensuring confidentiality was therefore important. To ensure confidentiality, all major identifying details have been removed (i.e. real names, places, company names, and street names) and replaced with pseudonyms where appropriate. Extra time to establish a trusting relationship with the participants was taken when needed and the interviews were carried out under the assumption that some participants may have felt fearful about the repercussions of the loss of confidentiality. Participants were also assured that any information they gave in the interview would not be linked to them in any way and would only be used for the purpose stated in the participant information sheet. Reasons that would require the researcher to breach confidentiality, such as disclosures of risk of serious harm or disclosure of criminal content, were discussed as part of this process.

2.6.3. Democratisation of the Research Process

The aim of the interviews was to allow participants to feel more able to expand on their own ideas, thus balancing the power relations between the researcher and the participant and democratising the research process. Using a semi-structured interview schedule therefore helped the researcher to interact with the participants in a sensitive way and made it possible to create an environment where ethical issues were kept at the forefront of the research process.

2.6.4. Potential Negative Consequences and Complaints Procedure

In case the interview brought up any difficult emotions for the participants, measures were put in place for these individuals to speak to a member of the mental health team responsible for their care. In dealing with potential difficulties during the interviews, a number of measures were taken. According to Smith (1995), having an interview schedule also helps the researcher to be more aware of what difficulties might arise during the interview. For example, in this study efforts were made to be sensitive about the use of the word ‘diagnosis’ as some participants may not have liked having their difficulties referred to in this way. The interview schedule was also designed to avoid ‘hit and run’ research by using warm-up and cool-down questions as recommended by Charmaz, (2006). An example of a warm-up question was: ‘How was your Journey here today?’ or ‘How long ago was it since your last saw you psychiatrist?’ At the end of the interview a series of questions was asked attempting to “ease” the participant out of the interview process, aiming to diffuse potential tension caused by the interview. An example of this was: ‘Is there anything you would like to ask me?’ or ‘Is there anything else you think I should know?’ Finally, where appropriate, psycho-education or signposting was offered.

3. Findings

The reported findings are based on the participants' accounts of their experience of receiving a diagnosis of bipolar disorder and the meaning they attach to this experience. There are three main parts to this section. In the first part a summary of the three master themes and related themes and sub-ordinate themes are presented. In the second part each theme is described in detail using verbatim quotes from the transcripts to illustrate their properties and how themes relate to each other. In the final part feedback from participants on the findings are presented.

3.1. Summary of Master Themes, Themes and Sub-Themes.

Table 2 provides an overview of the master themes and associated themes and sub-ordinate themes. In essence the findings from this study can be described in terms of three master themes: 1. 'Establishing fit between the diagnosis and subjective experiences', 2. 'Evaluating the utility of carrying the diagnostic label' and 3. 'The role of diagnosis in searching for solutions for one's difficulties'.

Table 2: Overview of the Master Themes and Subordinate Themes

<p>1. Establishing Fit Between the Diagnosis and Subjective Experiences (MT*)</p> <ul style="list-style-type: none"> • Diagnosis as Not Fitting (T**) <ul style="list-style-type: none"> ○ Not Identifying with Description of Mania (ST***) ○ Lacking (Accurate) Knowledge (ST) ○ Insufficient Client-Clinician Relationship (ST) • Diagnosis as Making Sense (T) <ul style="list-style-type: none"> ○ Diagnosis as Fitting Experiences (ST) ○ Possessing Accurate Knowledge (ST) ○ Sufficient Client-Clinician Relationship (ST)
<p>2. Evaluating the Utility of Carrying the Diagnostic Label (MT)</p> <ul style="list-style-type: none"> • Diagnosis as Stigmatising (T) <ul style="list-style-type: none"> ○ Public Stigma and Disclosure (ST) ○ Self-stigma (ST) • Diagnosis as Legitimising (T) <ul style="list-style-type: none"> ○ Diagnosis as Explaining Behaviours (ST) ○ Diagnosis as Understanding Self (ST)
<p>3. The Role of Diagnosis in Searching for Solutions to one's Difficulties (MT)</p> <ul style="list-style-type: none"> • Diagnosis as Cause of Disempowerment (T) <ul style="list-style-type: none"> ○ Losing Control and Being Dependent on Help (ST) ○ Worrying about Side Effects (ST) • Diagnosis as Cause of Empowerment (T) <ul style="list-style-type: none"> ○ Facing Difficulties and Accessing Help (ST) ○ Gaining a sense of Agency and Control (ST)

*MT=Master Theme; **T=Theme; ***ST=Sub-ordinate Theme

3.2 Master Theme 1: Establishing fit between Diagnosis and Subjective Experiences

This master theme emerged as consequence of participants being offered the diagnostic label by a clinician as a way to summarise, describe and account for their subjective experiences. For some participants, evaluating goodness of fit between the diagnostic label and one's own experiences was a process that occurred gradually over time while for others, receiving the diagnosis was a way of confirming what they already suspected. An evaluation resulting in a poor fit between personal experiences and the diagnosis increases the likelihood of the diagnosis being rejected by the service user, which in turn increases the likelihood of disengagement from mental health services altogether. Conversely, a good fit was pivotal in beginning the process of acceptance of the diagnosis and engagement with services.

3.2.1. Theme: Diagnosis as Not Fitting

This theme relates to experiences of the diagnosis as *not* fitting with participants' own understanding of their difficulties. In particular, some participants struggled to identify with the description of mania provided by the diagnosing clinician. In addition, a number of factors led to uncertainty about fit, including the quality of participants' knowledge and the quality of the relationship between participants and clinicians. While this theme stands in contrast to the theme 'diagnosis as making sense', participants did not exclusively identify with one or the other.

3.2.1.1. Sub-ordinate Theme: Not Identifying with Description of Mania

This sub-ordinate theme emerged as a result of participants attempting to make sense of the diagnosis offered to them. Some participants did not feel that the description of the diagnosis fitted with their experiences. Whereas most participants were able to recognise depressive symptoms, some participants struggled, in particular, to identify with symptoms of mania.

"The depressive side of things well I know if I am sleeping 20 hours a day and I know if I haven't brushed my teeth for a week or haven't washed in a week you know...I can see that but the other side I just cannot see." (P4, 434).

As illustrated by the quote above, some participants did not feel that the description of mania fitted with their own experiences. In this case, it was because this participant was unable to identify any of the manic symptoms within themselves. For other participants, not identifying with symptoms of mania was associated, not so much with being unable to identify the symptoms of mania within themselves, but rather with a reluctance to view their symptoms of mania as ‘problematic’ and warranting a psychiatric diagnosis.

“It’s easier to, when you are depressed, there is something wrong with me here. When you’re hyper, which still should be viewed as the opposite, well it is part of the illness but you’re having the time of your life, so when someone says don’t you think you should calm down a bit or do this, or have you taken your medication, or stop drinking, you don’t want to listen to that cause you’re having a good time.” (P9, 345).

Not viewing manic symptoms as problematic or something that requires treatment was prevalent in several accounts. For some participants establishing fit involved exploring which sub-type fitted their experiences most. For one participant, who did not identify with the description of mania, being re-diagnosed with bipolar 2 was important in terms of establishing fit.

“I think, very importantly, it was the first time anyone had ever said it’s... there are two types of bipolar. Because I think, for a long time I was really confused because I was thinking you know I really do identify with this to a great extent but on the other hand, you know, I don’t have this kind of...or very rarely had anything that could be called like a dangerous high.” (P2, 162).

As this quote also illustrates, participants’ own perception of what the diagnosis means (in this case that mania is associated with being dangerous), was important for establishing a fit between the diagnosis offered and participants’ perception of their own difficulties. The influence of participants’ own knowledge on fit was prevalent in most accounts and where this knowledge was either biased or incorrect, it could complicate the process of establishing fit as illustrated by the following theme.

3.2.1.2. Sub-ordinate Theme: Lacking (Accurate) Knowledge

Lacking knowledge about the diagnosis altogether or possessing inaccurate or biased knowledge about what bipolar disorder is, often resulted in difficulties establishing fit between the diagnosis and participants own experiences. For some participants, having experienced relatives going through a manic episode influenced their beliefs about what having a diagnosis of bipolar disorder means. Some participants were influenced by these experiences when building up their understanding of bipolar disorder. One participant described how she initially rejected the diagnosis but acknowledged that her reluctance to accept it was influenced by personal experiences of having a relative with bipolar disorder.

“So when they, when they actually diagnosed me, I just thought there is no way, there is no way that I can have this you know because like I said I mean I was there first hand and he had destroyed the place we were living in you know... so... Yeah, because I have only seen bipolar, the manic side of bipolar in a really destructive way and I knew that I wasn’t destructive.”
(P4, 62).

As illustrated by this example, participants use their personal experiences as a reference point for what bipolar disorder is and as such could be seen as having a limited or biased view of the disorder. Furthermore, if participants did not identify with these experiences, they were less likely to experience the diagnosis as fitting and as a result less likely to accept the diagnosis as a way of understanding their own difficulties. In addition to having a biased view of what bipolar disorder is, some participants also described just not knowing enough about the diagnosis to be able to establish a good fit.

“...even today I don’t really know what it means to be bipolar, I haven’t really done that much research. I just know that I have been diagnosed as bipolar and I have to take medication for it.” (P7, 133).

Not knowing enough about the disorder meant for some participants that they were more sceptical of the diagnosis accurately reflecting their experiences. Just relying on the clinician to provide them with the description of bipolar disorder was not always enough for participants. The next theme highlights the importance of the client-clinician relationship for the process of establishing fit.

3.2.1.3. Sub-ordinate Theme: Insufficient Client-Clinician Relationship

The quality of the communication between the participants and the diagnosing clinician emerged as a prerequisite for determining fit. An inadequate relationship often led to not feeling understood and not trusting that the diagnosis was made accurately. As illustrated above, participants at times found it difficult to recognise their own symptoms, a factor which complicates the process of establishing fit. However, even when participants were confident that bipolar disorder was the correct diagnosis for them, difficulties with communicating and explaining their difficulties to the clinician could cause delay in establishing fit.

“I think he has been observing me for the last seven years and because I find it difficult to explain some of the symptoms I am going through which I can’t explain which is difficult (laughs) you know I knew it myself but you know, I asked him myself, yeah I did, because I wanted to know if it was bipolar because all of the symptoms I got is linked to bipolar.” (P8, 123).

Establishing fit could also be influenced by the clinicians’ ability to communicate the clearly and explain the terms they use.

“...it’s still frustrating to me, I still want to know is it one thing or the other. I mean I think because I think I would be able to deal with it a lot better if I knew. If someone just comes up to you and say what is major episodes, what is that? It’s confusing you know. How are you supposed to pinpoint something if someone is just saying you have major episode you know, what is an episode (laughs).” (P8, 133).

As illustrated by the quotes above, not receiving clear and specific information from the psychiatrist about the diagnosis could lead to confusion. In addition, clinicians’ ability to create an environment that fostered openness was also seen as important in order for the service user to feel understood and a pre-requisite for establishing fit. When this was lacking, participants often felt that they had not been able to express their thoughts and feelings the way they wanted.

“It was more of a clinical environment. Dr. [Name of psychiatrist] was there. She is a... Dr. [Name of Psychiatrist] is a lovely lady, as you know, but she is a lovely person and [name of social worker] is a lovely guy, I know, but it was quite clinical and I didn’t really get a chance to sort of open up in a way that I would have liked possibly.” (P5, 201).

The potential for establishing a good fit was also influenced by contextual factors, such as the lengths of sessions. Having short sessions could cause participants to feel less confident that their experiences had been fully understood and the diagnosis being accurately made.

“I also find that the sessions are a little bit too short, like this is too short, by the time you getting down to something, you know, time is up and they’re very strict with their time limits, you know, it’s half an hour and I’d carry, I’d want to carry on talking and they were like, no we’ve got to end know, we’ve got other patients. So I did find the sessions were a bit short, you know, I would have liked a little bit longer.” (P7, 341).

Not having long enough sessions meant that some participants did not feel they had a chance to open up and talk about how they were feeling. In addition to the length of individual sessions, the frequency of sessions was also important in order to feel understood and establish fit.

“With the psychiatrist, I have only... I have only seen him four, five times in the last seven years. So it’s not been really an understanding if you see what I mean...” (P8, 383).

The context in which the diagnosis is imparted therefore also seems to have an indirect effect on establishing a good fit as some participants were left feeling that the psychiatrist did not fully understand their difficulties.

3.2.2. Theme: Diagnosis as Making Sense

While the theme and sub-ordinate themes described above highlights some of the difficulties in relation to establishing a good fit between the diagnosis and the participants own experiences, some participants also spoke about the diagnosis as fitting

with their experiences. Participants highlighted a number of factors that facilitated the process of establishing a good fit. For example, a good fit was more likely to occur when participants' own knowledge of the diagnosis and subjective experiences of their symptoms matched the description of the diagnosis provided by the clinician. Possessing accurate knowledge about the diagnosis and developing a good relationship with the clinician were key prerequisites for establishing fit. Each of these factors will be illustrated by the sub-ordinate themes below.

3.2.2.1. Sub-ordinate Theme: Diagnosis as Fitting Experiences

Many participants talked about the diagnosis as fitting their experiences. For many participants, establishing fit was hugely important for accepting the diagnosis and some participants described experiencing a sense of relief when receiving the diagnosis.

“What he was saying was exactly what I was experiencing and actually yeah, from that point of view it’s a huge relief.” (P3, 193).

Having experiences identified in this way was the first step towards accepting the diagnosis. Goodness of fit could lead some participants to identify with the diagnosis and speak of the diagnosis as an integrated part of their identity.

“I think what was really important was that this...when I met with [name of psychiatrist] he went...he really put his finger on it... And I thought that is definitely me.” (P2, 174).

“Yeah I did identify with a lot of them [symptoms of bipolar]. I can’t remember what they were at the time, but yeah, I did.” (P7, 289).

Obtaining accurate knowledge was important for establishing fit. This will be further explored in the theme below.

3.2.2.2. Sub-ordinate Theme: Possessing Accurate Knowledge

Possessing accurate knowledge emerged as an important factor as part of the process of establishing a good fit. Participants' knowledge and understanding of bipolar disorder came from a number of different sources including personal experiences, media influences and own research as well as information from professionals, service users

and relatives. Participants' understanding of bipolar disorder prior to receiving their diagnosis varied immensely from not knowing anything about the disorder to having done vast amounts of research. One way participants attempted to establish fit was through searching the internet.

"...my husband he went on the internet and there were like ten points, I can't remember what the points were but half of them matched me, it was like, yeah this is me, you know, exactly." (P7, 289)

While doing own research was important for establishing fit, this quote also highlights the importance of social support and illustrates how relatives often helped participants to make sense of their experiences even before having been to see a mental health professional. Carrying out their own research often meant that when participants came to see a psychiatrist, they already had a sense of expecting the diagnosis or just needing to have the diagnosis confirmed.

"...with my own research and being at day centre and talking to people that have got that condition, I clocked it, I just clocked it because the similarities and stuff like that and this is why I come to see the doctor...I just wanted to hear it from him. I knew but I wanted to hear it from him. I think you know your own mind and your own body and I just wanted to hear it from him." (P8, 248).

3.2.2.3. Sub-ordinate Theme: Sufficient Client-Clinician Relationship

As mentioned earlier, an insufficient relationship between client and clinician could cast doubt over the validity of the diagnosis. A good relationship between client and clinician was seen by most participants as an important pre-requisite for establishing a good fit between the diagnosis and participants own experiences. Here, clear communication between the participants and clinicians emerged as an important factor.

...they spoke to me very much on a level and there was no kind of pussyfooting around the issue. It's like, okay, this is probably what it is. And it was yes, I thought like it was a two-way process, like they were asking me genuine questions and I could...I mean we're kind of working

together towards finding a treatment and it's...and a plan that was going to work..." (P2, 89).

Apart from the usefulness of receiving clear communication from the psychiatrist about what they think is going on, this quote also illustrates the importance of collaboration between doctor and patient in exploring the nature of the distress and planning the intervention. Fit was also influenced by clients' perception of clinicians' expertise and knowledge of the diagnosis.

"...he was obviously a really intelligent guy and he knows his stuff and at each subsequent meeting a mean, I suspect he bothered to read back the notes before I turned up, it wasn't the case of him going, oh well hello who are you. It was kinda like it followed on from our conversation, which again, I mean I'm sure that's individual expertise..." (P3, 70).

Feeling confident in the clinician, created a sense of trust that the diagnosis was made accurately. In terms of the wider context, flexibility of sessions, in terms of length and frequency were seen as important in order to facilitate openness and understanding. Having flexible sessions created a sense of continuity and containment that fostered openness and confidence in the diagnosis being made accurately.

"I would have access if I wanted it, so it was very well dealt with...there was a huge amount of flexibility, really good. You know supportive, very sensitive being a bit nervous about things". (P3, 39).

"...usually it takes months and months or weeks and weeks. She seems to phone me back every week." (P6, 436).

3.3. Master Theme 2: Evaluating the Utility of Carrying the Diagnostic Label

This master theme emerged as a result of participants beginning the process of accepting the diagnosis. As part of this process, participants began to evaluate the consequences of endorsing the diagnostic label. Here the diagnosis was experienced or perceived as either predominantly stigmatising, leading to a reluctance to disclose the diagnosis to others, or as predominantly legitimising, leading to a readiness to disclose to others.

3.3.1. Theme: Diagnosis as Stigmatising

For some participants endorsing the diagnosis gave rise to a number of concerns relating to stigma from friends, family and work. In this way diagnosis was seen as a negative labelling of the person and caused people to be reluctant to disclose their diagnosis to others. In addition, this theme also illustrates how some people changed their view of themselves in a negative way.

3.3.1.1. Sub-ordinate Theme: Public Stigma and Disclosure

Experiences of overt stigma and discrimination only figured in a few accounts, but perceived public stigma as a result of receiving a diagnosis was a concern for most participants, particularly in relation to employment. Beliefs that employers would react negatively to the diagnosis caused many participants to want to conceal their diagnosis at work.

“Yeah, I don’t know if I would tell my employers and I was talking to my cousin’s husband and he was like you don’t need to tell, it’s none of their business, so I don’t know if I would say, I don’t know, it depends, I don’t know if it is relevant, I don’t know.” (P7, 412).

“I mean obviously from my point of view I wouldn’t have liked for it to go down on my record if I had mental health issues stamped on my public record as a result of it.” (P3, 242).

These quotes illustrate how participants worry about being stigmatised and of the consequences of disclosure. They also point to how participants adopt different positions in terms of how much control they feel they have over their diagnosis being made public knowledge. Regardless of which position is adopted, the reason behind wanting to keep their diagnosis to themselves is the same, namely the fear of being judged of being looked at in a different light.

“It’s the knowledge that, in my personal and professional life, like a large percentage to people will look at me differently if they know.” (P2, 555).

In addition to being viewed in a different light, some participants also expressed concern about being perceived as dangerous if they chose to disclose their diagnosis.

“...all the stigma that goes with it, you know. Like there’s no way, you know, I could go, and how an employer or...you know, half the people in my life just don’t know (Laughter) because they couldn’t know that. Because I know that it wouldn’t be accepted and people would think, you’re some kind of like dangerous lunatic.” (P2, 205).

As illustrated by the quote above, participants were not only concerned about stigma in relation to employment. Most people also worried about how the diagnosis would affect their personal relationships and whether or not to disclose their diagnosis. More specifically, some participants expressed a concern about revealing their diagnosis to their parents

“Anybody kind of, of older than our generation, I think, has a complete different view on it, and a complete different view on mental health, definitely. So...but yeah, I mean even people of our generation, if you don’t have the experience of it, I think those definitely still have a tendency to see it as weakness.” (P2, 397)

“Actually my mum was like horrified cause her vision of manic depressive illness is much more extreme, it’s like a view from the nineteen sixties you know before a lot of changes in mental health medication had taken place.” (P9, 322).

These quotes point to the possibility of a change in attitudes towards mental illness in the population in that the main worry about stigma relates to older generations, however they also serve as a reminder that experiences of actual stigma are still present for people who live with a psychiatric diagnosis.

3.3.1.2. Sub-ordinate Theme: Self-stigma

As illustrated above, receiving a diagnosis of bipolar disorder led some participants to worry about how the diagnosis would be perceived externally (i.e. by friends, family and work). This theme illustrates how some participants viewed themselves in a negative light as a consequence of receiving a diagnosis.

“I really did struggle with the label of it. And just...I’m not very good, anyway, of kind of asking for help and I mean not been strong enough, I guess. And it was quite difficult not to see it as a weakness.” (P2, 354).

In addition to having a view of themselves as weak as a consequence of having a diagnosis of bipolar disorder, some participants would also worry that receiving the diagnosis would mean that they would be more likely to become destructive or crazy.

“Yeah I think that’s the worry for me is that could I really act like that? You know could I be that destructive and aggressive.” (P4, 115).

“...from what I have gone through and the crazy things I have done. When I look at the symptoms of bipolar and can tell it’s probably, you can say I’ve got bipolar.” (P1, 352).

3.3.2. Theme: Diagnosis as Legitimising

While worries about stigma figured in all accounts, many participants also experienced the diagnosis as a positive way to explain their symptoms to friends, family and colleagues. Thus for some participants, having a diagnosis of bipolar disorder served as a way to legitimise their distress and explain their behaviours to others as well as themselves.

3.3.2.1. Sub-ordinate Theme: Diagnosis as Explaining Behaviours

The need for participants to explain some of their behaviours to friends and family was present in most accounts and for some people the diagnosis represented a welcomed explanatory framework.

“Well if I have known them [referring to her friends] for long enough, they would probably say, well that explains a lot.” (P1, 293).

In this way, participants used the diagnosis to explain their past behaviours and as a way to gain understanding from their family and friends and perhaps also maintain social relationships. Participants also recognised the potential to use the diagnosis as a way to explain current difficulties as illustrated in the quote below.

“...at least you can put a name to what you’ve got. When you go...when you get invited to things and you can’t go... You’re actually telling them that you are coming but the next thing you are telling them that you can’t, they actually know that you are lying; they need to understand that well I was low.” (P1, 256).

In addition to providing a way of explaining behaviours, some participants also felt that the diagnosis could be used to feel less responsible for their behaviours.

“It’s having just a concrete thing to refer back to. And it’s the freedom that goes with it. It’s the freedom of being able to say, this is something that I live with, and I’m not just kind of amorphously a bit depressed or not feeling right.” (P2, 591).

In addition to using diagnosis as a way to explain behaviours, this quote also shows how having a diagnosis can have the potential to ‘set someone free’ by externalising the causes of the behaviours and as a result also freeing oneself from responsibility and guilt associated with these behaviours.

3.3.2.2. Sub-ordinate Theme: Diagnosis as Understanding Self

While the sub-ordinate theme described above refers to how participants used the diagnosis to explain and legitimise symptoms to other people, this theme illustrates how participants used diagnosis to make sense of their own symptoms and to become less critical of themselves.

“Yeah, it could explain them. It wasn’t that I was just a grumpy person sort of thing, it was because...there was actually a chemical imbalance in my brain and you know that depression, mental illness is an illness and you can’t help it, so you’re...you know, you’re born with it.” (P6, 340).

Again, participants often found it helpful to externalise the ‘blame’ for feeling low or high by referring to bipolar as an inherited disorder, symptoms of which are caused by chemical imbalances in the brain.

“Although I think, particularly when I’m low, I’ll just revert to seeing it as being weak. But yeah, yeah, it has changed my relationship to them [symptoms]. So it’s sort of like, the diagnosis is, like, permission to go, okay, that’s what it is.” (P2, 252).

“Yeah, it explains a lot you know...its not either positive or..., it just makes more sense now...at least you’ve got an understanding of you know wait a minute. I’ve been called crazy, everyone going like [name of P1] is mad, [name of P1] is crazy, leave [name of P1] alone...” (P1, 377).

The last quote illustrates how, although diagnosis is not perceived as either a good thing or a bad thing, it is used to facilitate understanding and has the potential of being used as an explanatory de-stigmatising framework. However, some participants also used the used the diagnosis as a way of becoming more compassionate with themselves and more forgiving of past behaviours.

“It means I can accept it, understanding and get on with life a little bit more. Accept and proceed. Rather than erh just not understanding the way I am and making mistakes, I guess it’s a lot about mistakes and wanting to do good in the future and to a little bit more and maybe realise that I am not a bad person and hopefully take away some of the guilt, yeah, it means I can move on in life a little bit more positively.” (P9, 437).

3.4. Master Theme 3: The Role of Diagnosis in searching for Solutions to one’s difficulties

The final master theme represents participants’ desire to find solutions in light of their difficulties and following receiving the diagnosis. This process involves searching for medical and psychological treatments and was experienced in two ways: either as empowering, characterised by a sense of agency and control over one’s difficulties and leading to a readiness to engage with mental health services, or as disempowering, exemplified by feeling overly dependent upon medication and worrying about side-effects, resulting in a reluctance to engage with mental health services.

3.4.1. Theme: Diagnosis as Cause of Disempowerment

This theme involves descriptions of feeling out of control and worries about becoming dependent on medication and help in general. It also highlights the stress associated with the perception that medication may cause participants to lose part of their personality.

3.4.1.1. Sub-ordinate Theme: Losing Control and being Dependent on Help

When starting the process of accepting the diagnosis, some participants described a sense of losing control to the disorder. Participant 4 describes how she feared being taken over by the diagnosis.

“I want to carry on with normal activities and all and I want to be well and I want to, you know, so I look at it like it is a bit of a hindrance in that it’s there lurking and at any point it might drag me to my knees you know and that I don’t like...in any moment it can just overtake you. I don’t like that.”
(P4, 126).

When looking for solutions to their difficulties, some participants expressed a sense of not having any control over their treatment. Some participants describe the task of selecting the right medication as a process of trial and error, often leading to feelings of disempowerment and confusion.

“...at the moment I just feel like a guinea pig to be honest, this is how I feel and to start a new medication you know eh, I don’t know what effect this new drug is gonna have on my, I real don’t know.” (P8, 293).

In addition, participants were often left feeling worried about being over-reliant and dependent on medication.

“...the one thing that does worry me is the medication, how long will I need to be on medication for, you know, is it a long term thing, my mother in law she is like, no its a long term thing, I have to take them for the rest of my life. For the rest of my life, I don’t know if I can do it for the rest of my life...” (P7, 195).

“...this medication has been so good for me that I have also got a fear...I also have a fear of it being stopped that, you know, after a year or two I want to go back to CMHT and they are going to say to me, “Oh, you have been on this medication long enough now. We want to wean you off and see how you go from right there.” That fills me with dread. It really does because this medication is helping me to be me. So, that’s one of my fears for the future.” (P5, 459).

This last quote also illustrates the potential for never being able to cope with coming off medication and fearing relapse. In addition to fears of being dependent on medication that figured in participants’ account, many participants also expressed concern about the impact of the diagnosis on their close relationships. One participant expressed concern about the impact of her diagnosis on her partner and of being dependent on him.

“...he had said something about my husband being a carer and that for me was absolute. I mean I got out of the chair, I went to the window and I, ‘He is not a carer. Why would you say he is a carer?’ You know because in my head, a carer is somebody who pushes a wheelchair around you know and it really angered me that he was calling my husband a carer you know so I said to him, ‘He is not my carer’.” (P4, 229).

3.4.1.2. Sub-ordinate Theme: Worrying about Side-effects

While most participants acknowledged the need to take medication, most participants expressed concern about side effects. One participant expressed a strong desire to stay clear of medication as far as possible due to adverse side effects.

I was...I’m very concerned that, you know, you put weight on because I’ve been slimming for...I’ve lost a stone and a half. (P6, 46).

“I was on that for two weeks and I never had such an awful feeling. So I won’t really think that I wanna take the medication unless I am dying. You have blurry eyes, you fall asleep anytime. Its messed up you know what I mean?” (P1, 95).

This last quote also alludes to the potential for medication to have a negative impact of medication on participants' personality. This was also a concern for other participants. One participant feared that the medication would rob him of his creativity.

I just start questioning is that gonna take a... How much of my personality... How much of this illness is my personality, where are the lines, so it starts bringing in all sort of questions about identity and stuff like that. What will change under medication, how I will be different, will it. Creativity is everything to me... My job as a graphic designer and work long hours, I love to do it, its a compulsion almost... How will it [the medication] affect my thinking. (P9, 192).

Dr 'name of psychiatrist' said like, oh you'll never get that old persona back again, and I was like what? I was a bit shocked about what he said and I was like, What do you mean by that. He said, you will never go back to who you used to be (P8, 303).

This last quote illustrates that some participants also expressed a concern that any changes to personality caused by the medication would be irreversible. Furthermore, some participants feared that the medication would actually make their difficulties worse or even be a causal factor in developing bipolar disorder.

"I actually remember saying to [name of psychiatrist] one day, What if I don't have it and you're giving me these, these medicines that are going to interrupt the electric whatever it is between my brain and I am going to end up with bipolar when I never had it in the first place." (P4, 178).

Apart from worrying about side effects and the impact of taking medication on personality, some participants also expressed concern that the medication just was not going to work.

"There is a fear that it's not going to work, really." (P6, 132).

These quotes highlight how people can feel powerless in terms of trying to get better. The following master theme illustrates a different position adopted by many participants.

3.4.2. Theme: Diagnosis as Cause of Empowerment

In looking towards the future and searching for solutions many participants, in addition to expressing a sense of disempowerment and loss of control, also expressed receiving the diagnosis as a cause of empowerment. This was illustrated by participants feeling able to name their problems and face their difficulties, as well as accessing help and learning to manage their symptoms.

3.4.2.1. Sub-ordinate Theme: Diagnosis as Facing Difficulties and Accessing Help

This sub-ordinate theme illustrates the importance for participants to become aware of what they are dealing with in order to enable them to face up to their difficulties and look for solutions.

“...I kind of wanted to sort it. If it was bipolar, then I was going to accept that. I mean I wanted to find a long-term solution, and I don’t want to live with it...” (P2, 47).

This quote illustrates how a diagnosis inspired hope in terms of creating a possibility for a long-term treatment plan in spite of there not being any concrete plans for change in place. In this way, receiving a diagnosis became a way of containing participants’ difficulties and inspired feelings of hope for the future. For most people, the main reason for going to see a psychiatrist was that they wanted help to get better and receiving a diagnosis was seen by many participants as a means to accessing treatment.

“...it is a bit of a relief you know because I was going through highs and lows and not knowing and at least we know now and I can get treatment for it.” (P7, 186).

“Yes. When I need it, when I feel I need some help right now. That’s what counts for me personally.” (P1, 442).

“...without that diagnosis you are nowhere cause you are stuck, you are stuck without a diagnosis you are not getting no help, no support and it can go on for years and years and years.” (P8, 464).

In addition to receiving help from external sources and through receiving medication, participants also expressed a sense of agency and control in terms of managing symptoms themselves as illustrated by the theme below.

3.4.2.2. Sub-ordinate Theme: Gaining a Sense of Agency and Control

Some participants felt that receiving a diagnosis of bipolar disorder paved the way for them beginning to understand their difficulties better and as a consequence being more able to recognise and manage their symptoms.

“I think that the understanding of it is gonna stop me making some of the mistakes that I have made in the past. Therefore there is a brighter future because of it. More control and to realise what you do. Rather than thinking I am right all the time, it’s actually being able to see a different view on it, so OK maybe I should not make the decision right now, maybe I should come back to it in a week’s time.” (P9, 424).

“Yeah I can think about medication, I know I need to avoid people stressing me cause when they’re stressing me I get hyper.” (P1, 310).

The last quote illustrates how people use diagnosis as a way to think about what may trigger a depressive or manic episode and how to minimise the risk of this happening by avoiding certain stressful events. For some participants receiving a diagnosis facilitated the transition from dependency to independence.

“...if I get to the point where I myself can see triggers, I would be really happy. You know at the moment it is other people having to give me the information but if I can get to the point where I know myself and then I could do something about it then that is what really, that is my main goal for this.” (P4, 973).

3.5. Participant Validation

On completing the analysis all participants who had opted in during the initial interview were given the option to provide feedback on the findings. Participants were asked provide feedback in terms of whether or not the themes made sense, whether or not the themes reflected their own experience and if there is anything of importance that has not been included. At the time of submission only one participant had provided feedback. The following section outlines some of the responses from this participant.

Do the themes make sense?

“Yeah it does, it really does. You’ve hit the nail on the head. You’ve got the main three reactions to receiving the diagnosis.” (P2).

“I think in general I believe we are all on a continuum in terms of mental health and I can see myself reflected in all themes.” (P2).

Do the themes reflect your experience?

“Yeah, the three main continuums are precisely what I went through. I can really relate to them all, especially the stigma theme” (P2).

Is there anything important that is not included in the findings?

“I think the current mood state influences where I am on the continuum. I think I relate to the different themes and to the world depending where my mood is” (P2).

4. Discussion

4.1. Summary of Findings

Using a qualitative cross sectional design set within a social constructionist framework, this study aimed to get an in-depth understanding of service users' experience of receiving a diagnosis of bipolar disorder. A purposive sample of nine service users was used and in keeping with IPA's emphasis on ideography and phenomenology. This study utilised what Smith & Osborn (2003) termed a double hermeneutics and as such the findings can be viewed as the researcher's interpretation of the participants' interpretation of their experiences of receiving a diagnosis of bipolar disorder. The findings are supplemented with evidence in terms of verbatim quotes, which also served to delineate between participants' accounts and the researcher's own interpretation. In brief, the findings can be summarised in terms of three master themes: 1. 'Establishing fit between the diagnosis and subjective experiences', 2. 'Evaluating the utility of carrying the diagnostic label' and 3. 'The role of diagnosis in searching for solutions for one's difficulties'.

The first master theme is concerned with establishing fit and relates to participants' experiences of how well (or how poorly) the diagnosis offered to them fitted with their own experiences of their difficulties. Participants reported both experiences of good and poor fit. A poor fit was often associated with not identifying with symptoms of mania as described by the diagnosing clinician, whereas a good fit was often experienced as 'making sense' or 'confirming suspicions'. The degree to which establishing fit was possible was dependent on the quality of the therapeutic relationship and on participants' prior perception of the disorder. As such, participants were less likely to endorse the diagnostic label if they associated having bipolar disorder with being dangerous and if participants felt they were unable to open up to the clinician to the extent required to develop a mutual understanding of their difficulties. Finally for some participants, establishing a good fit was essential in order to begin the process of accepting the diagnosis.

The second Master theme was concerned with participants' perception of the utility of having a diagnosis of bipolar disorder and emerged as a result of participants beginning the process of accepting the diagnosis. This process set in motion a number of considerations around how useful (or not) having a diagnosis of bipolar disorder was

both in terms of participants' internal understanding of their difficulties but also in terms of the explanatory utility of the diagnosis when considering disclosure to friends, family and colleagues. In terms of negative consequences, participants spoke about perceived stigma and fears of being judged or discriminated against at work as a result of disclosing their diagnosis. Some participants also spoke about how a diagnosis had caused them to adopt a negative view of themselves as weak, dangerous or 'crazy'. With regard to positive aspects of receiving a diagnosis, participants spoke of how a diagnosis had helped them to develop a better understanding of their difficulties, to become more compassionate towards themselves and how diagnosis had provided them with a helpful framework for explaining certain symptoms or behaviours to others. In this way (perceived) stigma seemed to have an influence on participants' willingness/reluctance to disclose their diagnosis but it did not seem to influence participants' willingness to accept the diagnosis or engage with services.

The third master theme emerged as a consequence of participants searching for solutions to their difficulties. In thinking about the future and recovery, some participants talked about feeling disempowered, exemplified by feeling a lack of control over symptoms, worrying about becoming dependent on help and medication and worrying about the impact of medication on certain aspects of their personality. In contrast, some participants spoke about a sense of empowerment as a consequence of receiving the diagnosis in that they at least now knew what they were dealing with, which in turn opened up for the possibility of accessing help and learning to manage symptoms better. Receiving a diagnosis as a way of gaining a sense of control and hope about getting better was for some participants a key motivation for staying engaged with services.

4.2. Reflections on Participant's Validation

Following an initial draft of the result, participants who opted in during the initial interview were approached and given the opportunity to comment on the findings in terms of whether or not they made sense, whether or not they reflected their own experiences and finally if there was anything important that had been left out. At the time of submission only one participant had responded to this opportunity. The feedback from this participant was broadly in support of the findings in so far as the main themes was seen as making sense and being both broad enough and specific enough to capture the essence of the experience of receiving a diagnosis of bipolar

disorder for this participant. It was encouraging that this participant felt that they could recognise their experiences in the findings and that she did not feel that anything of importance had been left out. The feedback led to a number of interesting discussions. For example it was considered if the results would be best described as dichotomies or continuums. It was decided that presenting the finding in terms of dichotomies did not capture the fluidity of how participants move between different positions. The feedback from the participant suggested that describing experiences in terms of broader themes or continuums was more reflective of their experience. Indeed, this is a position that I can endorse as well. This debate is also reflective of the points raised in the introduction regarding the pros of cons of using distinct categories to describe human experiences or seeing mental health difficulties as lying on a continuum. Finally, it was highlighted that the mood state at the time of receiving the diagnosis and at the time of taking part in the interview might have influenced the responses given during the interview. It may be important to investigate this further in future research.

4.3. Importance of Client-Clinician Communication for Acceptance and Engagement

This study highlighted the importance of establishing a fit between the diagnostic label and personal experiences. The centrality of this theme in the present study is not reflected to the same degree in the literature, although elements of it do exist. For example, findings by Pitt (2009) highlighted diagnosis as ‘naming the problem’, in which participants spoke about the importance of personal experiences being explained by the diagnostic label. In this study, many of the participants spoke of the relief of being given a diagnosis that made sense and fitted their experiences. Equally participants also spoke of the distress caused by receiving a diagnosis which did not fit experiences. The importance of establishing fit is perhaps not a surprising finding for this particular client group as, according to Berk et al. (2007), the average time from onset to a diagnosis of bipolar disorder is over ten years. For many participants, the journey of receiving a diagnosis that made sense to them had been long and difficult.

Another aspect of this theme, which has not been reported in other studies, was the necessity of establishing fit for starting the process of accepting the diagnosis. In the present study, participants spoke of establishing fit as a prerequisite for beginning the process of acceptance. Whereas a good fit could lead some participants to identify with the diagnosis and speak of the diagnosis as an integrated part of their identity, a lack of

fit often led to rejection of the diagnosis and disengagement from services. In addition, this study also highlights the central role of the therapeutic relationship as a prerequisite for establishing fit. This is in line with research showing that good client-clinician communication has a positive impact on satisfaction and adherence (Cruz, 2002). In particular, this study found that the client-clinician relationship was viewed as positive when clients felt that they had been able to develop a mutual understanding of the presenting difficulties. This is consistent with a study by Rose (2001) which found that when the process of allocating a diagnosis was considered as one of negotiation, the person was more satisfied with their overall care. In addition to having a constructive dialogue between client and clinician, this study also highlights the importance of the wider context such as length and frequency of sessions. These findings echo research into the doctor-patient relationship and support the ecological model proposed by (Street and Millay, 2001), which argues that the communication is affected by personal attributes of both client and clinician and of the context within which the communication takes place. However, the importance of the client-clinician relationship highlighted in this study is not emphasised to the same extent in previous studies on psychiatric diagnosis. It is possible that the richness and detail by which participants were able to describe the communication between themselves and the diagnosing clinician, which made up a large component in this theme, may have been a consequence of participants being diagnosed within the last year. As such participants in this study may therefore have been in a better position to recall and comment on the specific helpful and unhelpful aspects of the therapeutic relationship.

The results from this study also highlighted the need for people to find solutions to their difficulties. This process involved searching for medical and psychological treatment and could be experienced either as empowering or disempowering. The empowering response was characterised by a sense of agency and control over one's difficulties and leading to a readiness to engage with mental health services, whereas the disempowering response was exemplified by feeling overly dependent upon medication and worrying about side-effects, resulting in a reluctance to engage with mental health services. Many participants highlighted the importance of collaboration and clear information giving as a key factor in gaining a sense of control and agency. In line with this, Mezzich (2007) advocates a person-centred and holistic approach which focuses on a person's strengths as much as their difficulties. The findings are also consistent with

recommendations from Rose and Thornicroft (2010) which highlight the importance of service users experiencing the allocation of a diagnosis as a process of negotiation.

4.4. Stigma and Bipolar Disorder

Another theme that emerged from this study, which echoed findings from previous research, was the presence of stigma in relation to receiving a diagnosis. For participants in this study, endorsing the diagnosis set in motion a process of evaluating the perceived consequences of carrying the diagnostic label. In this study, diagnosis was experienced both as stigmatising or legitimising. One of the main differences between findings from this study and those of other recent studies such as (Pitt, 2009; Hayne 2003; and Horn, 2007) was that participants in this study rarely reported actual experiences of stigma as a result of receiving their diagnosis. This may be a result of how bipolar disorder is viewed in society. Many participants spoke about the positive influences of the media, especially of celebrities being open about having the disorder. Some participants also spoke about how the manic side of bipolar was glorified or valued in certain areas of society. For instance one participant mentions how everyone in his line of work was ‘slightly crazy’ and that the creativity that is sometimes associated with manic phases was seen as a valued asset. When comparing the findings from this study to that of Horn (2007) and Pitt (2009), who looked at experiences of having a diagnosis of borderline personality disorder (BPD) and psychosis respectively, it is possible that the reason stigma seemed to figure less in the accounts of participants from this study is due to bipolar disorder generally being perceived in a less negative light in society. It is worth noting that participants in Pitt’s (2009) also reported feeling stigmatised by services and diagnosing clinicians, which did not emerge as a theme in this study, suggesting that stigma is less of a concern for this client group. Another explanation for the low levels of actual stigma reported in this study, could also be a consequence of participants only having had the diagnosis for a relatively short time and in some cases not having disclosed it to anyone and therefore not having been exposed to situation in which stigma might occur. This might also explain that the main way in which stigma figures in this account is through accounts of perceived stigma.

Perceived stigma was a key theme in this study. Perceived stigma was mainly associated with worries about disclosing the diagnosis at work as opposed to disclosing the diagnosis to friends and family. Most people in this sample were in full-time employment. One of the reasons for this might be that unlike other forms of stigma,

discrimination at work had the potential to pose a threat to participants' ability to provide for themselves and their family. As previously mentioned, participants were less worried about disclosing their diagnosis to family and friends. Perhaps participants felt in a better position to utilise the explanatory aspects of the diagnosis with their friends to gain sympathy and understanding. However, some participants did express concern about disclosing their diagnosis to their parents because of fears that the older generation might have a different, more negative view of bipolar disorder.

Another finding in this study in relation to stigma was the division between public and self-stigma which was initially proposed by Corrigan (2004). In general, public stigma was not associated with a cause for dis-empowerment as in the finding from Pitt (2009) or denial as suggested by Rose and Thornicroft (2010) but rather as a factor that influences decision on whether or not to disclose the diagnosis. However internalised sigma was often associated with being weak. Horn (2007) described how most participants internalised the judgmental and rejecting aspects of the diagnosis. However, in this study, it was not clear if self-stigma arose as a direct consequence of receiving a diagnosis or if it was mediated by experiences of public sigma. Of the participants who experienced self stigma, some had also experienced public stigma while others had not. This suggests that perhaps self-stigma is not just a consequence of internalised public stigma as suggested by Corrigan (2004). Perhaps participants' knowledge and personal experiences with relatives with mental health difficulties and experiences with mental health services also play a role.

In line with other studies, participants also spoke about positive aspects of diagnosis. However, as in the case of stigma, participants in this study predominantly spoke about the perceived benefits of having the diagnosis (as opposed to experienced benefits). Highlighted here was the potential for using the diagnosis as a way to explain past and current behaviours to others. This was also a central theme in the study by Pitt (2009) where diagnosis was seen as a helpful explanatory framework. In terms of facilitating a better understanding of oneself the benefits of receiving a diagnosis were clear. This also echoes finding by Hayne (2003) and Pitt (2009). In addition, this study also highlights the importance of developing a less critical and more compassionate and understanding stance towards oneself as a consequence of receiving the diagnosis.

4.5. Implications for Clinicians Imparting Diagnoses

In line with other studies carried out in this area (such as Pitt, 2009; Horn, 2007; Haynes, 2003), the findings from this study confirms the experience of receiving a psychiatric diagnosis as an important life event. It also highlights how a diagnosis can be experienced positively and negatively both within and across participants. Findings from this study have specific implications for clinicians in their role in imparting diagnoses. In particular, this study highlights the importance of establishing a good client-clinician relationship as an important prerequisite for being able to establish a fit between diagnosis and personal experiences, which is crucial if a diagnosis is to be endorsed by the client. Within this relationship, it is important that clinicians provide clients with as clear and unambiguous information as possible. If a good fit is established and the diagnosis can explain symptoms, it can feel de-stigmatising and containing for clients and is hugely important for beginning the process of accepting the diagnosis and for further engagement with services. This study also pointed out that it is important for the diagnosing clinician not only to get a clear idea of the symptoms experienced by the service user but also of their knowledge or experience of mental health difficulties in their families in order to address and dismantle any misconceptions that may be present. Bearing in mind the impact of distressing personal experiences of mental illness in the families of the clients and dismantling possible misconceptions may help these clients to feel less anxious about the prospect of endorsing the diagnosis and less reluctant to begin the process of acceptance.

For clients who feel a sense of stigma (or perceived stigma), results from this study have particular implications. For these clients, it is important that clinical interactions are characterised by trust and acceptance and diagnosing clinicians should use techniques such as externalisation to avoid clients feeling that they are to blame for their difficulties. Clinicians should also aim to phrase difficulties using service users' own words and avoid using stereotypical communication. The aim should be to normalise experiences and maximise the potentially positive role that diagnosis can have for service users while minimising the more negative aspects. For clients who feel a sense of disempowerment, it is also important that a diagnosis is imparted with a sense of hope for recovery and as such the diagnosis should be imparted and discussed as a positive tool to aid recovery.

The findings also suggest that it is important for diagnosing clinicians to bear in mind the wider context within which the diagnosis is imparted. Diagnosis should be given sensitively as part of a collaborative process where there is enough time within a session, continuity between sessions and frequency of sessions to allow the service user sufficient time to express themselves and feel understood. Allowing enough time to build up a good enough client-clinician relationship is crucial in helping clients feel safe enough to open up and talk freely about their experiences. Participants in this study often pointed to the sessions being too short or too infrequent to enable them to establish a trusting relationship with their clinician. Equally, when the parameters of the sessions were flexible, participants reported feeling understood and supported. It is therefore important that consultations are not rushed and that follow-up sessions are offered where needed.

While findings from this study have particular implications for diagnosing clinicians, they also have explicit implications relevant to Clinical Psychologists. Clinical Psychologists are well positioned and equipped to use research to inform clinical practice. One aim for the Clinical Psychologist could be to use findings from qualitative studies such as those from the present study to compile and develop best practice guidelines for diagnosing clinicians. In line with this, Clinical Psychologists could also be directly involved in providing training to other clinicians about, for example, the importance of establishing a good therapeutic relationship and how one might go about doing so. Following from that, Clinical Psychologists could also be involved in developing clinical trials to evaluate the impact of using such guidelines on clients' subsequent adjustment and engagement with services following receiving a diagnosis. Apart from training and research roles, Clinical Psychologists could also be more directly involved in the process of delivering diagnosis. One idea could be to offer follow-up sessions or to be involved in debriefing clients who find receiving a diagnosis particularly difficult or distressing. Within these sessions, psycho-education could be offered along with providing a different perspective, focusing on individual formulation of difficulties as an alternative to using diagnosis. Such interventions could increase a sense of empowerment and involvement for clients who perhaps struggle with accepting the diagnosis. Follow-up sessions could also be offered within a group-format. Here, Clinical Psychologists could take the lead as part of a multidisciplinary approach to understanding mental health difficulties, drawing on perspectives from different

professions. Such groups could be particularly useful in normalising symptoms and allowing service users to support each other.

4.6. Strengths and Limitations

This section will consider some of the methodological strength and limitation of this study in general and with particular reference to using IPA as a method of enquiry. One of the aims of IPA is to examine how individuals make sense of their experiences using relatively small homogenous samples. This can be seen as a limitation in terms of the generalisations and implications that can be drawn from such studies. When drawing conclusion from this study, it is important to note that the present sample is a purposive rather than a representative one. The homogeneity of this sample is reflected in the relatively little demographic diversity among the participants. For example, most participants could be considered to be fairly highly functioning, with seven out of nine holding down full-time jobs. In addition, it is also possible that the sample is slightly biased towards people who have had positive experiences of receiving a diagnosis. Most participants could be considered as having either fully or partially endorsed the diagnosis and no participants stated that they believed that they had been wrongly diagnosed. People who reject their diagnosis may have had a different experience of receiving it and may also have been less inclined to take part in the study and contribute to these findings. However, in recruiting, efforts were made clarify that the accuracy of the diagnosis was not paramount. Rather, what was of interest in this study was people's experience of what it feels like to have one's experiences explained in terms of a diagnosis of bipolar disorder regardless of the accuracy of the diagnosis. In spite of some of these potential shortcomings in relation to the sample it is important to note the purpose of qualitative research. The aim of this research was not to make general statements of 'truth' about peoples' experiences. Rather, it was to provide an in-depth understandings and interpretation of people's individual experiences. In this way, having a small fairly homogenous sample could also be viewed as a strength. We believe that this study makes a valuable contribution to our knowledge about the impact of receiving a psychiatric diagnosis by extending our knowledge specifically to people who have recently received a diagnosis of bipolar disorder.

In terms of data collection, it is recognised that the interview schedule might have had an influence on some of the themes that emerged in this study. However, the interview schedule was used flexibly, allowing participants to shape the nature of the

conversations and efforts were made not to use leading questions. In addition, all participants were asked if there were anything that had not been included in the interview which they felt were important for understanding their experiences. This also allowed novel areas to emerge, which, due to the flexibility of qualitative approaches, allowed the researcher to follow up on unexpected areas. In this study, the interview schedule was based on previous research findings and discussion with experienced supervisors. As mentioned earlier, this study could have benefitted from inviting a group of service users to shape the interview schedule prior to the data collection. It is possible that omitting this stage has had an effect on findings. Involving service users at this point in future studies is likely to improve the relevance of questions and prompts.

In terms of the analysis itself, it is acknowledged that this analysis is likely to have been influenced the researcher's own perception and understanding of the topic under investigation. Although the researcher is seen a central to the analytical process in IPA, efforts were made to ensure the quality and transparency of the analysis through peer review in the form of inviting an external researcher to code one of the transcripts and in discussing findings with supervisors. Inviting an external researcher to code a transcript provided way of comparing and contrasting contrast coding from different researcher. As discussed earlier, this study could have been improved if the external researcher had been involved earlier so discoveries from this process could have been used to inform subsequent data collection and analysis. Another potential limitation was the use of a professional transcription service for some of the interviews. As discussed, this may have influenced the familiarity with these particular accounts. For this reason it is possible that the analysis for these four transcripts was slightly less rigorous. Future studies would benefit from minimising external transcription to ensure the highest level of personal involvement with all transcripts.

One of the main strengths of this study was utilising a qualitative research paradigm. Using IPA as a method of enquiry allowed for an in-depth exploration of participants' experiences and meant that each account was given equal importance. Analysing each interview in detail served to improve the rigour of the study, ensuring that each participant's account was represented in the final results. Having a relatively small sample size ensured that there was enough time for this depth of analysis and that the voices of all participants were heard, thus meeting the idiographic commitment of IPA (Smith et al., 2009). A particular strength of this study, especially given the lack of

research into the area, was the emphasis on service users being able to shape the nature of the enquiry by being asked to feedback on the interview. This resulted in changes to the interview schedule, to make questions more pertinent.

4.7. Suggestions for Future Research

This research study benefited from an in-depth analysis, focusing on *one* specific psychiatric diagnosis, namely bi-polar disorder. Given the differences highlighted above between the finding from this study and other qualitative studies focusing on other diagnoses, it is likely that future research would continue to benefit from focusing on *one* specific diagnostic group at a time rather than investigating psychiatric diagnoses in general. Larger scale qualitative studies may also benefit from comparing and contrasting how two different diagnoses are imparted and received. Most qualitative research in this area has used grounded theory or IPA as the method of choice. However, due to the importance of the communication between clients and clinicians highlighted in this study, it is possible that Discourse Analysis may prove to be a useful tool for future research projects aiming to further understand the way language is used when diagnosis is imparted. As such, Discourse Analysis may increase our understanding of how service users and clinicians use language to construct the difficulties experienced by the service users and of how consensus between service users and clinicians is achieved. The therapeutic relationship is vastly under-researched in relation to how diagnosis is imparted and future research would undoubtedly benefit from exploring this further. The richness with which the communication between clinicians and clients is described by participants in this study was most likely a result of only interviewing service users with a recent diagnosis. It is therefore likely that studies wishing to explore the client / clinician communication would benefit from focusing service users who have recently received their diagnosis.

While focusing on participants with a recent diagnosis may produce richer data in relation to the therapeutic relationship, it is possible that experiences of the recovery process would benefit from widening the sample to include participants who have had their diagnosis for longer. While the present research highlighted the importance of perceived stigma and the impact of this on disclosure, there were relatively few accounts of actual stigma experiences. Studies wishing to investigate the impact of stigma in relation to living with a psychiatric diagnosis are therefore also likely to

benefit from widening the sample to service users who have had their diagnosis for longer.

Further quantitative work could follow from this study. Using qualitative methods on unexplored areas with a small sample allows the researcher to get an in depth understanding of the most important aspects of topic under investigation. However small exploratory studies such as the present study have limitations in terms of generalisability and there is clearly also a need for larger quantitative studies investigating the impact of receiving different diagnosis with a representative sample. One suggestion for future research would be to use the themes from qualitative studies to develop questionnaires which could then be distributed to larger samples. Following from this, Factor Analysis could be used to further refine these questionnaires. Such questionnaires may be useful in evaluating the quality of the care provided by diagnosing clinicians. Another suggestion would be to use themes from qualitative studies to develop best practice guidelines. This would enable researchers to develop clinical trials to evaluate the impact of using such guidelines on clients' subsequent adjustment and engagement with services.

In relation to investigating the recovery process following diagnosis, it might also be important to measure participants' perception of how much they feel supported by their social network as a predictor for positive adjustment. Most participants in this study highlighted the importance of a good social network in coming to terms with the diagnosis.

In relation to bipolar disorder specifically, one aspect that might be important to consider is the impact of the current mood state on how participants react to receiving a psychiatric diagnosis and how they recollected their experiences. None of the participants in this study were either going through a manic or depressive phase during the interviews but many participants stated that their answers might have been different if they had been in a different mood-state. In addition, some participants stated that the mood state at the time of receiving the diagnosis influenced their initial reaction to it. Future research may benefit from sampling for diversity in terms of current depressive / manic symptoms and comparing levels of satisfaction between these groups using thematic analysis in respect to the way in which the diagnosis was imparted.

4.8. Conclusion

The primary aim of this study was to gain an in-depth understanding of service user' experience of receiving a diagnosis of bipolar disorder. Nine participants with a recent diagnosis of bipolar disorder were interviewed using a semi-structured interview schedule and transcripts were analysed using IPA. Three master themes were identified in relation to people's experiences of receiving a diagnosis of bipolar disorder. These were: 1. 'Establishing fit between the diagnosis and subjective experiences', 2. 'Evaluating the utility of carrying the diagnostic label' and 3. 'The role of diagnosis in searching for solutions for one's difficulties'. Results broadly support findings from previous studies but differs in terms of the central position the process of establishing fit between diagnosis and personal experiences has as well as the relevance of perceived stigma for this particular group of participants. The study also highlighted the importance of the role of the client-clinician relationship in terms of establishing fit and instilling hope which has implication for acceptance of the diagnosis and engagement with services. We believe that this study has added to the literature in terms of analysing in-depth the experiences of people who have been recently diagnosed with bipolar disorder. There are important clinical implications of how diagnoses are given, as well as room for much future research in this area.

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Appendix 1: Ethical Approval

NHS
National Research Ethics Service
NRES Committee London - Surrey Borders
St Georges University of London
South London REC Office 1
Corridor 1 - Room 5.13
1st Floor, Jenner Wing
Tooting
London
SW17 0RE
Telephone: 0208 725 0262
Facsimile: 0208 725 1897

Date: 10th November 2011

Mr Kasper Sandgaard Pallesen, Trainee Clinical Psychologist
Camden and Islington NHS Foundation Trust
Addiction Sciences Building
3rd Floor, 4 Windsor Walk,
Denmark Hill,
London, SE5 8AF

Dear Mr Sandgaard Pallesen

Study title: Service Users' Experience of Receiving a Diagnosis of Bipolar Disorder.
REC reference: 11/LO/1311
Protocol number: 1

Thank you for your letter of the 13th October 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a sub-committee of the REC at a meeting held on the 6th November 2011. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
NHS.uk

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		30 th September 2011
Covering Letter - Email		7 th November 2011
Evidence of insurance or indemnity		9 th July 2010
Evidence of insurance or indemnity		29 th July 2010
Evidence of insurance or indemnity		8 th August 2011
Evidence of insurance or indemnity		15 th August 2011
Letter of Invitation to participant	1	12 th July 2011
Other: Participant Debrief Sheet	1	12 th July 2011
Other: Student Investigator CV - Mr Kasper Pallesen	1	12 th July 2011
Other: Dr Diana Rose - Academic Supervisor CV	1	12 th July 2011
Other: Dr June Brown - Academic Supervisor CV	1	12 th July 2011
Other: Interview Documentation Sheet	2	30 th September 2011
Other: Semi Structured Interview Schedule	2	30 th September 2011
Participant Consent Form	3	7 th November 2011
Participant Information Sheet	3	7 th November 2011
Protocol	1	12 th July 2011
REC application	IRAS 3.1	29 th July 2011
Referees or other scientific critique report	1	12 th July 2011
Response to Request for Further Information		13 th October 2011

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

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the National Patient Safety Agency and Research Ethics Committees in England

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

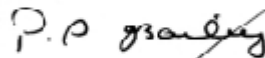
Further information is available at National Research Ethics Service website > After Review

11/LO/1311

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Dr Hervey Wilcox
Chair

Email: lsbrec@stgeorges.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: Ms Jenny Liebscher, Governance & Delivery Manager
Institute of Psychiatry
Room W1.08
De Crespigny Park
London, SE5 8AF

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NRES Committee London - Surrey Borders

Attendance at Sub-Committee of the REC Meeting held on the 9th November 2011

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Wendy Brooks	Stroke Nurse Consultant	Yes	
Canon Christopher Vallins	Regional Chaplaincy/ Adviser	Yes	
Dr Hervey Wilcox	Consultant Chemical Pathologist	No	

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the National Patient Safety Agency and Research Ethics Committees in England

Appendix 2: Participant Information Sheet

**Institute of
Psychiatry**

at The Maudsley

Kasper Pallesen
Department of Psychology
Third Floor ASB PO78
Institute of Psychiatry
London SE5 8AF
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Email: kasper.sandgaard_pallesen@kcl.ac.uk

KING'S
College
LONDON
Founded 1829

Study Title:

Service Users' Experience of being Diagnosed with Bi-Polar Disorder.

My name is Kasper Pallesen and I am a Trainee Clinical Psychologist studying clinical psychology at King's College London. I would like to invite you to take part in my research project but before you decide if you want to take part or not, I would like to make sure that you understand why this research is being done and what it would involve for you. You may take as long as you need in order to make up your mind about whether or not you wish to take part in the study and I am happy to go through this information sheet with you and answer any questions you might have.

This information sheet is divided into two parts. Part one gives you information about the purpose of this study and what will happen to you if you chose to take part. Part two gives you more information about the details of the study. After reading through this sheet and if you are unsure about whether or not to take part you are welcome to take the sheet with you and talk to others about the study if you wish.

Part 1: Information about the purpose of the study.

1.1 What is the purpose of this study?

The purpose of this study is to give service users an opportunity to share their experiences of receiving a diagnosis of bi-polar disorder as there is little research in this area. I am interested to hear about your personal experiences regarding being diagnosed, your understanding of the diagnosis and how you feel having a diagnosis might impact on you in the future. It is your opinion and feelings that are of interest and there are no right or wrong answers. This research is mainly educational in that it seeks to increase understanding of what it feels like to receive a diagnosis of bi-polar disorder but it may also provide you with an opportunity to reflect on your own experiences.

1.2 Why have I been invited?

You have been invited to take part in this study because you have recently been given a diagnosis of bi-polar disorder. I am looking for participants from all backgrounds. However, in order to take part in the study you must be between eighteen and sixty four years old. I aim to interview around 20 people from St Giles and Lordship Lane Community Mental Health Teams (CMHT).

1.3 Do I have to take part?

No you do not have to take part. It is up to you to decide if you want to join the study. I will describe the study and go through this information sheet with you and if you would like to take part, I will then ask you to sign a consent form. You are free to withdraw at any time during the interview, without giving a reason and this will not affect the care you receive in any way. You can take as much time as you need to make up your mind. Please feel free to take this information sheet with you and discuss it with other people, if you wish.

1.4 What will happen to me if I take part in this study?

If you decide to take part, I will first ask you to fill in a consent form. I will then arrange with you a convenient time for you to come in to St Giles or Lordship Lane community mental health team to take part in an interview with me about your experience of receiving a diagnosis of bi-polar disorder. During this appointment I will ask you to fill in an interview documentation sheet containing a few questions about you (such as age, gender, and time since you were diagnosed). The interview itself should take around one hour and will be recorded using a dictaphone. After the interview I will ask you if you would like some more information from me about bi-polar disorder or if you would like me to set up an appointment with your care-coordinator or the psychiatrist who informed you about the diagnosis to discuss any issues that may have come up during the interview. In addition to the interview, I will ask if you would like to also come in for a one hour group discussion with other participants from this study to discuss the initial findings of the study. If you wish, I will also send the final results to you and invite you to attend another one hour group discussion with other participants to comment on the final results. In order to take part in this study you would only be required to take part in first session, the two additional sessions are optional. Any sessions you attend with me will be in addition to any care you would otherwise receive at the community mental health team.

1.5 Expenses and Payment.

As a thank you for taking time to participate in this project you will be given £10 in cash at the end of the individual interview session. You will have to pay for your own transportation to and from any session you attend with me and you will not be paid for attending the discussion group regarding the initial findings or the discussion group to comment on the final results.

1.6 What will I have to do?

If you would like to take part in this study it is essential that you participate in the one hour long interview about your experiences of being diagnosed with bi-polar disorder. You will also be asked if you would like additional information about the diagnosis, if you would like to speak to a member of your mental health team about any issues that may have come up during the interview, and if you would like to take part in a discussion group regarding initial finding or feedback group regarding the final results of the study. To participate in this study it is only essential that you take part in the initial interview.

1.7 What are the possible disadvantages of taking part in this study?

Sometimes talking about personal experiences can leave people feeling exposed and vulnerable. If the interview or meetings bring up any difficult feelings for you an appointment can be arranged for you to see your care co-ordinator or the duty worker at the community mental health team you belong to. Also remember that you can pull out of the study at any time, which will not affect you care in any way. In addition, after the interview I can also provide you with additional information regarding bi-polar disorder.

1.8 What are the possible benefits of taking part in this study?

I cannot promise that taking part in this study will benefit you. Some participants may use this experience to reflect on their own experiences in relation to their diagnosis and their care in general. In addition, the information you provide may help other people receiving a diagnosis in the future. The results of this research project may increase awareness of particular issues around receiving a diagnosis of bi-polar disorder and generate further discussion amongst clinicians and service users about what may be useful to the individual service user when receiving a diagnosis of bi-polar disorder.

1.9 What happens when the research project finishes?

When the research is finished, I will write a report which will be part of my doctorate thesis in clinical psychology at King's College London. If you wish, I can send you a summary of the study and the findings at a later date.

1.10 What if there is a problem?

If you feel that any part of the research project has upset you in any way or if during the interviews, you raise concern about the care you have received, I will discuss with you how you would like to take things forward. If you agree, an appointment can be set up between you and your care-coordinator or the psychiatrist that informed you about your diagnosis. More information about making formal complaints is provided in part 2.

1.11 Confidentiality.

Information you provide will be kept confidential. I will follow ethical and legal practice and all information about you will be handled in confidence. Further details about confidentiality are included in Part 2.

~~~

*If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.*

## **Part 2: Further details about the study.**

### **2.1 What happens if I do not want to carry on with the study?**

You can withdraw from the study at any time and this will not affect your care in any way. If you choose to withdraw from the study, I will destroy all your identifiable information including any voice recordings, interview documentation sheets and transcripts. However, if the results have already been written up and I have used any of the information you have provided me with, I will not be able to remove this information from the result section.

### **2.2 What if there is a problem.**

If you have a concern about any aspect of this study, you can speak to me in person or contact me on 020 7848 0223 and I will do my best to answer your questions and address your concerns. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital or clinical team. You can also contact the South London and Maudsley NHS Patient Advisory Liaison Service (0800 731 2864; pals@slam.nhs.uk) or the Trust's Research and Development office (0207 848 0790). In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against King's College London but you may have to pay your legal costs. The normal National Health Service (NHS) complaints mechanisms will still be available to you (if appropriate).

### **2.3 Confidentiality**

All information which is collected about you during the course of the research will be kept strictly confidential. With your consent I would like to record the interview, transcribe it and possibly use direct quotes from the interview in the final report. All interview recordings and transcripts will be kept confidential and recordings will be destroyed after transcription. No quotes with information that could identify you will be used. In addition, all identifying information will be changed in the transcripts, so individuals cannot be identified. Any other identifiable information will be stored in locked cabinets or on pass-word protected computers or memory stick and will only be available to authorised persons (such as the researcher, the sponsor, regulatory authorities and research and development office in order to monitor ethical and qualitative aspects of the study). Identifiable data will be stored in locked cabinets until the end of 2012 after which it will be destroyed. In addition, anything you say about your care will also be kept confidential. If you express any concerns about the care you have received, I will ask you if you would like to discuss this further with a member of the team responsible for your care. I would only be obliged to breach confidentiality if you tell me something that gives me cause to believe that you may pose a risk of serious harm to yourself or others, or make a criminal disclosure which requires action, including passing information to others. In this case, the research team will take action as appropriate. Where possible, we would aim, to discuss this process with you.

### **2.4 What will happen to the results of this research project?**

The results will be part of my main project of my doctoral thesis in clinical psychology, which I aim to publish in a scientific journal. No participants will be identified and any quotes used as part of the final results will be anonymised. A summary of the project can be sent to you if you wish.

### **2.5 Who is organising and funding the research?**

This research is sponsored by King's College London.

## **2.6. Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, in order to protect your interests. This study has been reviewed and given favourable opinion by the London - Surrey Borders Research Ethics Committee.

## **2.7 Further information and contact details.**

You may want further information about this study or about whether or not to take part. If so, please see the following details below.

For further information about research in general and specific information about this particular research project, please contact:

Kasper Pallesen (Trainee Clinical Psychologist)  
King's College London, Department of Psychology, Institute of Psychiatry  
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For further advice on whether or not to take part in this study or talk to someone if you are unhappy with the study and do not want to speak to the researcher about this, please contact your care co-ordinator or the duty worker at St Giles or Lordship lane Community Mental Health Team:

St Giles Community Mental Health Team  
St Giles House  
St Giles Road  
London SE5 7UD  
Tel: 020 3228 2767

Lordship Lane Community Mental Health Team  
20-22 Lordship Lane  
London SE22 8HN  
Tel: 020 7525 6100

Please do not hesitate to ask any further questions. Many thanks,

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Please keep a copy of this participant information sheet and a signed consent form.

Appendix 3: Consent Form

Patient Identification Number: _____

Title: Service user's experience of being diagnosed with Bi-polar disorder

Name of Researcher: Kasper ~~Palliser~~

Please Initial box

1. I confirm that I have read and understand the participant information sheet dated 30/09/11 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my care or legal rights being affected.
3. I understand that relevant sections of my notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
4. I understand that all information I provide for this study is being used for research purposes only.
5. I understand that all the information provided by me will be kept confidential and all names, places and other identifiable information mentioned in the interview will be changed to insure no links to individuals can be made.
6. I understand that direct quotes from the interview may be used in the write-up of this study but that no quotes with information that could be linked to you will be used.
7. I understand that the interview will be recorded and that the tape used for the interview will be destroyed as soon as it has been transcribed.
8. I understand that I can request a copy of the interview transcript if I so desire and that a summary of the findings will be available to me at a later date.
9. I agree to take part in the above study.

This research is being supervised by June Brown (Consultant Clinical Psychologist) Psychology Department (PO77), Institute of Psychiatry, De Crespigny Park, London SE5.

_____ Name of Participant	_____ Signature	_____ Date
_____ Name of Person taking consent	_____ Signature	_____ Date

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Appendix 4: Interview Documentation Sheet

Date of the interview:
Place of the interview:
Duration of the interview:
Ethnicity of the interviewee:
Gender of the interviewee:
Age of the interviewee:
Profession of the interviewee:
Name of Diagnosing Psychiatrist:
Time since diagnosis:
Current treatment, if any:
Current medication, if any:
If on medication, How long have you been on it:

Appendix 5: Semi-Structured Interview Schedule.

Warm-up Questions

- **Demographic questions, journey time, familiarity with service etc.**
- **Practical questions regarding diagnosis**
 - Time since diagnosis. Current treatment and medication. Time on medication

1. Can you tell me about your experience of getting a diagnosis of Bi-polar Disorder (Your experience)

- Prompt: Difficult
- Prompt: Relief

2. Do you feel you understand what the diagnosis means? (Your understanding)

- Prompt: Uncertainty about what the diagnosis means
- Prompt: Did you feel it was explained in a way that you understood it?
- Prompt: Did you feel that you had the opportunity to ask questions?
- Prompt: Did you know much about the diagnosis beforehand (i.e. from the media or other sources)

3. Do you feel that the diagnosis has altered the way you view / understand yourself? (Does it fit?)

- Prompt: Diagnosis as not fitting
 - At all
 - Not fitting into subgroup
- Prompt: Naming the problem
 - Explaining experiences
 - Legitimising stress
 - Externalising problems
- Prompt: Labelling the person
 - Experiencing labelling
 - Creating a spoiled identity

4. Does the diagnosis alter the way you feel about your perceived difficulties and the future? (implications)

- Prompt: Do you think you will find having a diagnosis helpful?
- Prompt: Where you given any treatment plan?
- Prompt: Do you think your friends and / or family would treat you differently if they knew of your diagnosis?
- Prompt: Knowledge as power
 - Diagnosis providing focus and a sense of control
 - Knowledge withheld and others as experts
- Prompt: Diagnosis as rejection
- Prompt: Hope and the possibility of change
- Prompt: Confidence and self-esteem
- Prompt: Means of access
 - To treatment
 - To care support and understanding
- Prompt: Cause of disempowerment
 - Failure to disclose
 - Lack of information
 - Prognosis of doom
 - Predominance of biomedical model
 - Over-reliance on medication
 - Lack of cultural awareness
- Prompt: Cause of social exclusion
 - Social stigma
 - Media stigma
 - Discrimination by employers

Cool down questions

- Focus on strengths, plans for the day etc.

Appendix 6: Example of an Interview Transcript

Initial Annotations

Emerging Themes

- 1 I: Yeah. Okay. So you said about four months, you've
2 been on medication?
- 3 P2: Yeah.
- 4 discussion with [name of psychiatrist] as well? Or was
5 that... (Overlapping Conversation)
- 6 P2: Yes. Yeah, yes.
- 7 I: That's about four months prior. And did he start you
8 on it straightaway then or?
- 9 P2: Yeah.
- 10 I: Okay. So I guess the first kind of question would just
11 be, if you can think about...you said there'd been
12 maybe three psychiatrists you've seen?
- 13 P2: Uh-hmm.
- 14 I: So two kind of recently and then one earlier on.
- 15 P2: Yeah.
- 16 I: If you can think about just those sort of times, how'd
17 you describe the experience sort of in general, sort of
18 what's been...how's it been like?
- 19 P2: I think most recently it was much more positive.
- 20 I: Okay.

Being put on medication straight away

*Having different experiences with
psychiatrists*

Having different experiences with psychiatrists

Having positive experience resulting partly from own attitude to diagnosis

Having a sense of agency

When younger not wanting to be different

Having no sense of agency

Awareness of not being 'normal'

Not feeling well

Starting to accept diagnosis

Resisting and avoiding possible diagnosis

Age and symptoms influencing experience

Psychiatrist not understanding

Having positive experience of seeing a psychiatrist

21 P2: And I think that's at least kind of 50% down to my
22 attitude, to the bipolar and to what I wanted to achieve,
23 like when I want to speak to somebody.

24 I: Okay.

25 P2: I think...sort of back in the day when I was...I
26 think I was probably about 19 or 20, the first time I
27 spoke to anybody, and I really didn't want that to be
28 anything wrong with me, so I went along (Laughter)
29 okay. I was sort of aware that this isn't normal and that
30 I'm...I don't think I'm very well. But once this... once
31 it kind of started to be approached, it's that I came on to
32 think, "Maybe this is what it is," I kind of shut down
33 completely and pushed it away and didn't want to
34 know.

35 I: Right.

36 P: And I also think that I do feel that maybe because of
37 my age, and the fact that just the way that some
38 symptoms of hypomania present...I think....I didn't get
39 on with this psychiatrist that I saw, and I got the
40 impression they saw me as kind of a bit of a girl really.

41 I: Right. Okay.

42 P2: And so, yeah, more recently I've kind of been
43 positive because I've kind of seen Hugh Jones with
44 this...kind of set idea that, you know, enough is

Not wanting anything to be wrong

Wanting to know, wanting to change

Readiness to accept

Wanting long term solution

*Clinician and personal readiness
being important for acceptance*

*Difficulty in navigating health care
system when young
Getting conflicting advice*

*Upbringing influencing willingness to
accept diagnosis (diagnosis seen as
failing)*

*Resistance leading to confusion and
reluctance*

45 enough, really. And I kind of wanted to sort it. If it
46 was bipolar, then I was going to accept that. I mean I
47 wanted to find a long-term solution, and I don't want to
48 live with it so, yeah.

49 I: So it's partly...so partly it was...it sounds like there's
50 something about how the clinician or the psychiatrist
51 has viewed you, and partly it was to do with your own
52 kind of willingness to accept something more open
53 appropriate.

54 P2: Definitely yeah.

55 I: So those are the two....

56 P2: Yeah. I mean I think, kind of trying to navigate the
57 mental health system when you were a young adult is
58 quite difficult, and that it was...yeah, I was sort of
59 getting sort of conflicting advice from lots of different
60 areas.

61 I: Yeah.

62 P2: And then I think because of (Laughter) I mean my
63 own kind of very Northern upbringing kind of made me
64 think I was really failing. But I didn't want to see
65 anybody at all so there was sort of numerous factors
66 that contributed to my own kind of confusion and
67 reluctance around it. But yeah, I think once I was open
68 to do it, to the idea. And once...and I think...once I

Diagnosis as long-term solution

Upbringing influencing readiness to accept

Diagnosis seen as failure

*Severity of episode influencing
readiness to accept
Severity of episode as justification
for presenting to clinicians*

Needing to take symptoms seriously

*Being on even footing with clinician
as helpful
Receiving unambiguous
informations
Communications as a two-way
process
Being asked genuine questions*

69 had a couple of really severe episodes actually as well.
70 And it wasn't just...yeah. Once it was kind of
71 embedded, that it was probably quite serious. I think
72 there were some things for the clinicians to look at and
73 go, okay, alright.

74 I: Yeah. There is something....

75 P2: Yeah, there's something there something I need to
76 take seriously.

77 I: Okay. And what was kind of, if you were to think
78 about those two, it's like sort of at first themselves and
79 then the more recent one where you were seeing
80 someone. How would you kind of describe the
81 difference between the way that you said about have
82 your own approach to it and your...perhaps
83 something...you've experienced something that maybe
84 there was something that was different or something to
85 be taken serious, how would you describe the
86 difference between the clinicians in terms of how they
87 were?

88 P2: How they were with me? I felt that when I was
89 doing the doing the...they spoke to me very much on a
90 level and there was no kind of pussyfooting around the
91 issue. It's like, okay, this is probably what it is. And it
92 was yes, I thought like it was a two-way process, like
93 they were asking me genuine questions and I could...I
94 mean we're kind of working together towards finding a

*Severity of episode influencing
readiness to accept*

*Importance of feeling on equal footing
with doctor*

*Importance of receiving unambiguous
information*

*Working together to find treatment
and sustainable plan
Previously feeling like a nuisance
Meeting with psychiatrist not being
collaborative*

Importance of not feeling patronised

Not feeling judged as important

Feeling judged

95 treatment and it's...and a plan that was going to work,
96 whereas before I kind of felt like a bit of a nuisance.
97 And because I couldn't...I think with the first guy that I
98 saw, I remember him...just being like what do you
99 think it is. It's like, wha--?

100 I: Right, okay.

101 P2: And I was like, that is so... (Laughter)

102 I: Right. Yeah. So there's something about a
103 collaboration that was good but also that there was a
104 very kind of straight talk, you know, "This is what we
105 think."

106 P2: Yeah. And not talking me like I was stupid
107 (Overlapping Conversation).

108 I: Yeah. Yeah.

109 P2: So I think that was definitely my initial experience.
110 So yeah, I felt there was no kind of judgment in the
111 (Overlapping Conversation).

112 I: No, no. Yeah, yeah.

113 P2: Yeah. Right. There I was feeling quite judged.

114 I: And do you think that's to do with the clinician or
115 your own kind of coming to terms with things or what?

*Importance of working together to find
treatment*

Importance of not feeling judged

*Becoming more at peace with
symptoms
Practical focus as important*

*Trying not to be ill
Attempting to pretend to be normal*

*Putting self in stressful situations as
punishment
Working hard, choosing wrong job*

Choosing wrong people to be with

116 P2: Both. I think as I've matured, I've become a lot
117 more at peace with it. And I've become a lot more able
118 to say, well, it doesn't really matter what I wanted to be
119 if it is what it is. And, yeah, I'm kind of happy to just
120 stay with the practical.

121 I: Yeah, yeah. So would you say that it was a difficult
122 experience or was there sense of relief around, let's say
123 the most recent experience?

124 P2: Around getting the diagnosis?

125 I: Yeah.

126 P2: It was both. I think in my case I'd kind of....It's
127 sort of a couple of years before I got the diagnosis. I'd
128 adopted there a strategy (Laughter) where I decided that
129 I was just going to try really hard not to be ill, and
130 pretend, you know because if I act like a normal then,
131 then it will just happen. And then obviously it became
132 this huge burden and I couldn't just pretend to be
133 (Laughter) normal. But I kind of...I almost kind of
134 deliberately fallen in with people and put myself in
135 situations that were very stressful, because I was kind
136 of punishing myself for not being normal, sort of thing.
137 So it was, like, I got a really awful, demanding job that
138 didn't suit me at all. And I hang out more and more
139 and more with people that were...they were really
140 judgmental and like, and you just...you know, the first
141 sign of weakness in anybody, they'd really come down

Importance of having a practical focus

<p><i>Ambivalence about diagnosis</i></p> <p><i>Having difficult feelings about diagnosis</i></p>	<p>142 on it, and I was like, “Well, this will kind of beat me</p> <p>143 into shape (Laughter) and I’ll be normal. And I think I</p> <p>144 kind of got to breaking point. But anyway, but I think</p> <p>145 when I got the diagnosis there was definitely like half</p> <p>146 of me that went, oh shit, I can’t....</p>	
	<p>147 I: So all this is, you’ve tried to fight and to resist...?</p>	
<p><i>Resisting diagnosis</i></p>	<p>148 P2: Yeah. And I just didn’t...I really didn’t want it...I</p>	
<p><i>Questioning identity</i></p>	<p>149 didn’t want that to be who I was and what I was. I had</p>	<p><i>Resisting diagnosis and questioning identity</i></p>
<p><i>Ambivalence about diagnosis</i></p>	<p>150 that kind of standard confusion about, you know, is this</p>	
<p><i>Needing to change</i></p>	<p>151 who I am, is it, like, a part of me and what is it? Does</p>	
<p><i>Needing long-term solution</i></p>	<p>152 it define me? But then, on the other hand, like, the</p>	
<p><i>Facing diagnosis</i></p>	<p>153 whole point of kind of seeking out what I did was</p>	
<p><i>Viewing bipolar as a chronic disease</i></p>	<p>154 because I’d come to the realisation that I couldn’t go</p>	<p><i>Diagnosis as long-term solution</i></p>
<p><i>Not going away but manageable</i></p>	<p>155 on. And I needed that kind of long-term solution and</p>	
<p><i>Facing diagnosis as means to treating it</i></p>	<p>156 that I needed to kind of face it. And I think since I did</p>	
<p><i>Identifying with aspects of bipolar</i></p>	<p>157 – as soon as I kind of looked in the face, went, all right,</p>	<p><i>Diagnosis as means to accessing treatment</i></p>
<p><i>Not identifying with mania (importance of fit)</i></p>	<p>158 this is what’s going on – I kind of see it as just like a</p>	
	<p>159 chronic disease, really; just go on. It’s not going</p>	
	<p>160 anywhere but I can treat it. And because I’ve looked it</p>	
	<p>161 in the face I could treat it for what it is. So yeah, relief.</p>	
	<p>162 And also, I think, very importantly, it was the first time</p>	<p><i>Identifying with diagnosis sub-types</i></p>
	<p>163 anyone had ever said, it’s...there are two types of</p>	
	<p>164 bipolar. Because I think, for a long time I was really</p>	<p><i>Not identifying with mania</i></p>
	<p>165 confused because I was thinking you know? I really do</p>	
	<p>166 identify with this to a great extent. But on the other</p>	
	<p>167 hand, you know, I don’t have this kind of...or very</p>	

*Easier to accept sub-type
Subtype seen as just being a bit odd*

Importance of fit

Diagnosis as fitting

Diagnosis as making sense

*Diagnosis / symptoms as being part of
self
Identifying with positive aspects of
bipolar*

168 rarely had anything that could be called like a
169 dangerous high.

170 I: Yeah, yeah, yeah.

171 P2: And so what is it, all right? Am I just a bit odd.
172 (Laughter)

173 I: Yeah, yeah.

174 P2: So yeah. It was...yeah, I think that was really
175 important was that this...when I met with [name of
176 psychiatrist] he went...he really put his finger on it.

177 I: Yeah.

178 P2: And I thought that is definitely me.

179 I: Yeah, it makes sense if you were that way.

180 P2: Yeah, definitely.

181 I: o you said something about defining yourself. Could
182 you share a bit more about the experience of whether it
183 does or doesn't or how you relate to it?

184 P2: Yeah, I guess it's just difficult because it is so much
185 part of who I am. And I'm sure other people say this,
186 but a lot of very positive things I've done have been as
187 a result of bipolar. I mean I've...like I love the crazy
188 work that I've done, and a lot of the academic work that
189 I've done. I think it's helped me, really. And I think

Diagnosis as fitting experiences

Diagnosis as fitting experiences

Diagnosis as making sense

*Identifying with positive aspects of
bipolar*

*Extreme experiences leading to
being non-judgemental
Having to grow up quickly*

*Feeling isolated when experiencing
extreme emotions
Feeling special. Feeling drawn to
people with similar experiences*

Bipolar as part of who you are

*Bipolar as part of self
Feeling stigma*

*Not wanting to disclose to people or
work*

Stigma and dangerousness

*Having to change lifestyle in order
to get better
Affected by changes
Resenting having to change*

190 that my experiences of kind of being at extremes
191 emotionally, and the fact that that's led me to extremes
192 in other ways as well, I think it's made me a very
193 nonjudgmental person. And it's definitely made me
194 grow up and quite quickly, I think. And it's always
195 like, you know, like when you're in the throes of a high
196 or a low, you really think like nobody else could
197 possibly feel like this, and this is...you know, I'm
198 special. And you identify that. I mean I'm drawn to
199 people...like my very closest friends all have some
200 form of this. (Laughter) And you do end up, kind of,
201 yeah, that it just becomes so much part of the fabric of
202 your being. And then on another side as well, but you
203 just think, oh god, this is me, like all these who are
204 close to me because I can't...because I am bipolar and
205 all the stigma that goes with it, you know. Like there's
206 no way, you know, I could go, and how an employer
207 or...you know, half the people in my life just don't
208 know (Laughter) because they couldn't know that.
209 Because I know that it wouldn't be accepted and people
210 would think, you're some kind of like dangerous
211 lunatic. So yeah, this is...it's a difficult one. And also,
212 I think when I decided that I was going to really tackle
213 it, like I say, I thought, you know, I'm going to have
214 start looking at the way I live my life, like sweet, silly
215 things like eat properly, sleep properly, exercise, sort
216 everything out, like keep it in mind, like keep a mood
217 diary. And that...that really affected me, actually, for a

*Not wanting to disclose diagnosis at
work*

Worrying about being accepted

*Worrying about being perceived as
dangerous*

Other people suggesting bipolar tendencies

*Name being less important
Positive aspects of having bipolar diagnosis. Not changing relationship with symptoms*

218 while. I think I'm just starting to kind of get used to
219 that now, but like I really resented it. I thought you
220 know, like, why would I have got to do...why
221 this...and change the way I live...?

222 I: And is that something that's happened since the
223 diagnosis, these kind of changes?

224 P2: Yeah. Yeah.

225 I: So do you think this sort of idea that it's that, it's
226 helped you be creative and it's...like a kind of positive
227 identity or identified with it? Has that changed by
228 having the diagnosis as opposed to...would you
229 identify different with those parts of you or...?

230 P2: I'm not sure. I think I always....I mean for years,
231 like, it was at the back of my mind that this....You
232 know; it was suggested to me even before I ever went
233 and spoke to somebody that perhaps I had bipolar
234 tendencies, or whatever. And so it's always been in the
235 back of my mind that, you know, this is...call it what
236 you want, but this is helping me kind of...it makes me a
237 better writer, a better actor, to think....So I don't think I
238 would necessarily have identified it with any...like, just
239 because of the diagnosis.

240 I: No. And in an either a positive or negative way, I
241 mean has it...while also thinking whether it had

*Worrying about having to change to
manage symptoms*

*Diagnosis as helping to see bipolar
as symptoms rather than weakness*

*Perception of bipolar changes as
mood changes*

Going easy on yourself

242 any...have negative? I'm talking a bit about the kind of
243 stigma around it.

244 P2: Whether the diagnosis had any negative effect?

245 I: So in terms of thinking about you kind of relating to,
246 when you're feeling a little bit high or a bit low, has
247 that – putting a name to it – made you think differently
248 about those times, or...?

249 P2: It's definitely made...it's made me see it as a
250 symptom rather than a weakness.

251 I: Right.

252 P2: Although I think, particularly when I'm low, I'll
253 just revert to seeing it as being weak. But yeah, yeah, it
254 has changed my relationship to them. So it's sort of
255 like, the diagnosis is, like, permission to go, okay,
256 that's what it is.

257 I: Right.

258 P2: And to cope that I tell, like, myself, cut myself
259 some slack.

260 I: Okay.

261 P2: And go, it's all right if you don't...you know,
262 achieve today. (Laughter) You just have to go to work.

263 I: Yeah. So it helped you to be less hard on yourself?

Diagnosis as not being weak

*Diagnosis as being more
companionate towards yourself*

*Having a good understanding
Doing own research*

Doing own research

Constant noise in head

264 P2: Yeah, very much.

265 I: Okay. And what's your kind of understanding about
266 diagnoses and...in particular bipolar? How is that?
267 Was that kind of explained, or how do you feel your
268 understanding of this?

269 P2: You know...of the condition, or the diagnosis?

270 I: Yeah. Yeah, I guess...yeah, of both I suppose as
271 well. (Laughter)

272 P2: I guess I mean...of the condition I think...I hope
273 my understanding is reasonably good. (Laughter) I did
274 my own research about this as well, you see.

275 I: Yeah. What beforehand or...?

276 P2: Yeah, beforehand, during, (Laughter) after. Yeah I
277 keep it going, the idea is to kind of know the enemy
278 but...I mean my understanding of my experience of it
279 is that I get probably three to four quite severe episodes
280 of depression in a year. Interspersed with these periods
281 of hypomania where I'm...like I said...but this is...the
282 best way, if I had to describe it, is like I have a constant
283 noise in my head and the noise changes from being,
284 like really zingy, and like ideas bouncing off each
285 other, and that there's beautiful kind of constricted
286 symphony. To...when I'm depressed, just like...kind
287 of like any time I'm, like... White noise...really loud

*Doing own research as gaining
knowledge*

Having three more severe episodes

Describing different sub-types

Diagnosis as fitting

*Being told that symptoms were not
fitting diagnosis*

288 white noise. And there's kind of clamour in your
289 voices just telling me how cross I am. And yeah, that's
290 essentially kind of how, I guess, I lived until I started
291 treatment. And then I had, yeah I had normally three
292 kind of episodes of something that was kind of closer to
293 mania. And but that's my understanding of how this
294 type of bipolar functions I have those kind of big lows,
295 semi highs and but without the kind of it's not like, it's
296 rapid cycling, it's not. And it's not huge mania.
297 (Laughter)

298 I: Do you feel like things were explained in that session
299 that you had with psychiatrists, or did you feel that you
300 kind of knew enough about it, or...?

301 P2: Certainly by the time I spoke both to you and
302 [name of psychiatrist] actually and then like I said, with
303 you, it's the first time that anyone had kind of brought
304 my attention to bipolar to you specifically and it was
305 interesting to know that it's something that seems to be
306 on the rise as well. And....

307 I: And you felt that that, did that fit more with your
308 experience of how things were?

309 P2: Yeah, much more, much more. I mean I've never
310 been told. It must have been when I was at university,
311 being told that I couldn't be bipolar because I didn't
312 have the kind of full on... which, yeah, that's one of the
313 things that sort of threw me, and stopped me coming

*Importance of diagnosis fitting
experiences*

*Experiences seen as symptoms
Diagnosis not changed relationship
to experiences*

314 back for help for so long, because I obviously had
315 thought (Overlapping Conversation). There's a name
316 for it I thought I was just being really weird.

317 I: But how...and how like who would say those
318 that...like that...? Would that...?

319 P2: One of the doctors that I saw.

320 I: Oh, one of the doctors. Sure, yeah.

321 P2: Yeah.

322 I: And do you feel that it's...I suppose you'd talked a
323 bit about this before but why...that you kind of...that it
324 puts...that it makes you understand your highs and
325 lows in a different way or...like having a name to it?

326 P2: I'm not sure. I don't think...other than what we'd
327 said...I mean I'd go about kind of seeing them as just
328 symptoms. But yeah, it hasn't made me look at them
329 differently. But I guess that is quite a big shift, really.

330 I: To seeing them as symptoms and you mentioned
331 something about kind of not so being hard on yourself
332 perhaps.

333 P2: Yeah, I think...yeah, I guess it has changed it,
334 really because of I did two things I said. I wasn't
335 going...I've tried to kind of remove anything that's
336 going to affect my mood too dramatically. So things

Seeing experiences as symptoms of bipolar and as means to remove things that affect mood

Diagnosis as causing changes to lifestyle

Diagnosis as framework for understanding symptoms and changing behaviour

Getting used to label

Used to struggle with label

Seeing diagnosis as sign of weakness (self-Stigma) and societal stigma

Bipolar as big part of identity

337 like drinking too much and getting enough sleep, and
338 those kind of things. So it was important to be able to
339 isolate, okay, I'm actually heading for a phase or is
340 it...you know. And also yeah, once I am feeling a bit
341 either way, to treat it as something that is part of...of
342 the bipolar...it is part of me, and yeah, we let it happen
343 to an extent and not, yeah, not kind of beat myself
344 through, like 16-hour days (Laughter). Yeah, I expect
345 myself to be over due with that.

346 I: And is there anything...so in some ways it's been
347 helpful to think about it as symptoms, and getting a bit,
348 perhaps more understanding towards yourself. Has
349 there been any kind of negative impacts of it? Other
350 than with the psychiatrist, when you talked about it,
351 where you felt that some things weren't right about it,
352 or in a sense, then?

353 P2: Yeah, I mean I think, no one would be able to do
354 that. (Laughter) I struggle less with this now but I really
355 did struggle with the label of it. And just...I'm not
356 very good, anyway, of kind of asking for help and I
357 mean not been strong enough, I guess. And it was quite
358 difficult not to see it as a weakness. And I think, just in
359 terms of other people in our society, it's a huge shame
360 that...say, part kind of deciding what the bipolar was
361 and how much it defined me was this realisation that,
362 whoa, it's actually a massive part of me, and it's
363 something I just can't tell anyone about. And it's, you

Seeing Diagnosis as sign of weakness

Not being able to disclose
Haing to take medication
Having to go through therapy

Not feeling able to share due to stigma

Bipolar as taking a prominent presense

Negative media coverage
Bipolar as blanket term
Lack of understanding
Societal stigma

Media facilitates stigma

364 know I'm going to be going through like...I'm going to
 365 be taking medication for...ever, really (Laughter) and
 366 you know, going through therapy, and it's going to be
 367 something that I have to think about all the time. And
 368 I'm like; I can't share it with so many people that are in
 369 my life, because of the stigma that it holds. And...it's
 370 like when you're trying to get pregnant and (Laughter)
 371 then everybody that you see is pregnant. Like
 372 suddenly, everything that I read seemed to be about
 373 bipolar in one way or another and it's just the way that
 374 it's presented. Like you know, Kerry Katona and, you
 375 know, people that I've known in my life that have been
 376 really quite ill. And the way that they were able to talk
 377 about it and...you know.

378 I: And what is your kind of experience of it being
 379 talked about in the media?

380 P2: Really negative. I guess it's just become a new
 381 blanket term, I think. It kind of...because there's no
 382 understanding of it and no understanding that is
 383 encouraged, it makes it sound like this, you know a
 384 disease, that people should be, you know, put into
 385 asylums for; it's actually (Laughter). And it's not. It's
 386 just something that you have to live with. And it's like,
 387 yeah. And it's been incredibly detrimental to being
 388 able to talk to this, especially to my family, about.
 389 Because you know, my stepdad thinks Daily Mail is
 390 codswallop, so. (Laughter)

Not feeling able to disclose

Not feeling able to share due to stigma

Worries about stigma in society

Importance of close support network

Societal and generational stigma

Bipolar as weakness

*Not expressing concerns about stigma
in clinic. Not being able to cope with
more than the diagnosis*

391 I: So yeah, has been hard to speak to people about it.
392 Yeah.

393 P2: I mean that I've been very lucky with...I've got a
394 very close circle of friends and all of you had been
395 incredibly supportive, and all of you have some
396 experience of it. But...my partner's been great as well,
397 but...so, yes. Certainly, like...anybody kind of older
398 than our generation, I think, has a complete different
399 view on it, and a complete different view on mental
400 health, definitely. So...but yeah, I mean even people of
401 our generation, if you don't have the experience of it, I
402 think those definitely still have a tendency to see it as
403 weakness.

404 I: And were you able to express some of those kind of
405 concerns in the clinics, just out of interest. Did he talk
406 about the kind of impact of diagnosis, or...?

407 P2: Not really. Not really, I don't think.

408 I: And is it something that you would have liked or...?

409 P2: Yeah, I think it probably would ...yes and no,
410 because I, you have... I don't think I could cope
411 (Laughter) Right, what's wrong with you? (Laughter)

412 I: Yeah, okay.

413 P2: And what did...?

Bipolar seen as a weakness

[Type a quote from the document or the summary of an interesting point. You can position the text box anywhere in the document. Use the Text Box Tools tab to change the formatting of the pull quote text box.]

414 I: Yeah.

415 P2: And I think in the circumstances, it's, yeah. I mean
416 everything that (Overlapping Conversation).

417 I: You probably would have. Yeah, yeah.

418 P2: Yeah.

419 I: And have you just seen them once or twice or...?

420 P2: Twice. And then...yeah, by that time I'd been
421 referred down to the other end and...from my GP,
422 so...pretty much, yeah.

423 I: So I think that kind of last...okay, anyway,
424 I've...would you might have something else you want
425 to add, that I haven't thought of? But the kind of, one
426 other thing I was thinking about was – and you
427 probably talked a bit about it already – was this idea of
428 how having a diagnosis, of being diagnosed, how that
429 might impact on your future. We talked a bit about the
430 fact that you've been about to work and your friends.
431 Who would you tell? What and when and how much?
432 I don't know whether you think or not, it's been
433 helpful, do you think it's been helpful? Do you think it
434 might be helpful in the future? So what are the
435 positives and negatives around...?

436 P2: Yeah, it's a big one...oh, god. I mean...I think
437 like....A pretty kind of constant struggle I have with it

*Worries about the future and coping
and stigma at work*

438 is that I know there are a lot of people who, like, look at
439 me and think that I've got potential that I'm just not
440 realising. Because, like, I did...I did well
441 academically, I did well creatively, and you know, it
442 was like sort of when I finished my master's that I think
443 it was sort of expected that I'd carry it on going to
444 academia when I would...you know, choose the other
445 way and go off and be about this and that. But can I
446 cite it with being ill? (Laughter) Because I kind of...I
447 did worry sometimes about...you know, will I never be
448 fulfilled because I'm always going to be kind of
449 combating this thing. Will I be able to make money, be
450 able to put myself through...

451 I: Those who did...does having the diagnosis kind of
452 more formally – I haven't talked about that – did that
453 change...

454 P2: Yeah.

455 I: ...the way that you see the future in terms of what
456 humanity or...?

*Diagnosis as means to developing a
plan*

457 P2: Yeah, it does. I think in the same what that it's
458 very positive, I think that I can know what is and I can
459 plan accordingly. Sometimes when I put it in those
460 terms it scares me and I think is it defeating me?

461 I: In what way do you mean?

Worries about stigma at work

Diagnosis as planning for the future

Worries about holding a job down

Stepping away from responsibilities

*Not wanting other people to be
affected by bipolar*

Diagnosis as cementing problems

*Wanting children
Having to come off medication
during pregnancy*

462 P2: In what I can commit to.

463 I: Right.

464 P2: And can I have any responsibility over people and
465 over you know, I need money and I need (Laughter)
466 because you know is it just...and it has kind of got to
467 the point before when I've made responsibility work.
468 Just got, oh, god, I'm just going to go now and be crazy
469 for a few months now and I mean I don't want that to
470 be the case and I think definitely, since in the last year
471 and a half, I've definitely kind of stepped away from
472 responsibility for that reason and I've kind of felt it's
473 probably beneficial so they won't...because I don't
474 want, I just don't want anybody to really be disrupted
475 by my bipolar. But yeah, it...I mean in terms of work
476 and career future, that scares me, and I think, makes me
477 think negatively, having had a diagnosis because I
478 think, well, it's set in stone now.

479 I: Right. Okay. So whereas before you were kind of
480 battling a bit with it and there's something more...it
481 was like slightly different about than having the...?

482 P2: Yeah, definitely. And kind of more holistically
483 like...I probably want to have children at some point.
484 How's that, you know, I have to come off medication
485 when I get pregnant. Are my chances of postnatal
486 depression going to go through the roof? And
487 how...you know, I don't really know my dad very well

*Worrying about consequences of
diagnosis on ability to work*

*Worrying about managing medication
and wanting to have children*

Worries about post-natal depression

Having diagnosis and thinking about the future

Having diagnosis as ambivalent

Diagnosis as a way facing up to issues and having agency

Diagnosis as scary

Importance of facing up to difficulties

488 but I'm pretty sure that, you know...and I know he...I
489 know he was sectioned I know he's had sort of quite
490 severe mental health problems. And I'm pretty sure
491 that it's similar to this. What if I pass that on? So
492 it's...yeah, it definitely kind of...it has made me think
493 quite hard about my future.

494 I: So there's something about having a name as well
495 that's positive in that you get some kind of agency.

496 P2: Yeah.

497 I: But also negative in the sense that there is realisation
498 that comes within it as well.

499 P2: Yeah. There's a kind of, I think it always...it
500 always has to be more positive to know what you're
501 facing and you always get more agencies as a
502 result...but in amongst that it's all that kind of
503 (Laughter) scared stuff.

504 I: I mean is there other ways do you think there would
505 be more helpful in terms of naming something like
506 this?

507 P2: So this is the author in me now, but...no, I think
508 you just have to go to what it is. It's not nice so I don't
509 know if anyone's going to like it. But I think...yeah. I
510 don't know how you could possibly go about making it
511 better or making it nice, so you just have to....

Diagnosis as facing difficulties

Diagnosis as having more agency

Being discriminated against

Honesty vs disclosure

512 I: Are there any other implications for kind of having a
513 diagnosis or having it more explicitly? Because it
514 sounds like you kind of known for a while and, you
515 know, part of you resisting but...and is there is any
516 other implications for you, do you think, in terms of
517 maybe other treatment of other parts of your life?

518 P2: Oh, I guess the...I guess the work thing actually
519 and I had no experience so I did a languages degree.
520 And when you go on your year abroad the main thing
521 that everybody does is to go off and be a language
522 assistant in the school. So, I applied for this scheme. It
523 was about time that I was kind of first seeking help, and
524 they refused me. The British Council refused me
525 because they said I'd be a danger to children (Laughter)
526 which was a massive blow. And I think that kind of....

527 I: Was that because you disclosed something?

528 P2: Yeah, because they said...they said something any
529 kind of... I can't remember what it is but it was in a
530 section on application forms, and I was kind of, I was
531 going through a phase of being really honest about it
532 (Laughter). And so I said "Yeah I'm seeking help."
533 And then there was this kind of flurry of emails
534 between me and the admissions girl. And she made me
535 answer all these horrible intrusive questions about
536 myself (Laughter). I don't think...I mean, that
537 was...that was when it was sort of first being floated

Worrying about disclosure

Being forced to use diagnostic label

538 that it might be bipolar. And I think just even that
539 reaction to it, and...because these people at the British
540 Council, they're into something ridiculous like 99.7%.
541 And it was like, you know, nothing to do with, like, my
542 academic credentials. It was the suggestion that I might
543 be a bit bipolar (Laughter). So I think I mean...

544 I: And did you use those terms with them?

545 P2: I had to by the end of it because it kind of...there
546 was this whole big kind of investigation (Overlapping
547 Conversation)well not investigation but she I remember
548 being emailed reams of really searching questions
549 about what exactly, you know, if you could vouch for
550 my sanity and things. So it was I think....

551 I: So you've had some of the experiences of stigma?

Worrying about stigma

552 P2: Yeah. And it's that kind of....for me, that probably
553 is the biggest thing.

554 I: Yeah.

Worrying about being stigmatised

555 P2: It's the knowledge that, in my personal and
556 professional life, like a large percentage to people will
557 look at me differently if they know. And I think it is
558 one of those one of the last to... and just
559 completely...it's a completely ridiculous experience
560 (Laughter).

*Worrying about stigma as the most
important thing*

*Considering other people's
reactions to knowing the diagnosis
as both positive (explanatory) and
negative (stigmatising)*

*Viewing diagnosis as positive
Anticipating worry*

561 I: And do you think...I suppose this might relate to you
562 as well, but do you think that they would...because
563 presumably they would have...your friends or your
564 colleagues would have kind of seen you on a low or say
565 on a high. And do you think that by giving their name,
566 they would view that differently? Even though they
567 maybe seeing might be seeing you same...does that
568 make sense?

569 P2: I think people go one of two ways. I think...I've
570 had experience of literally just being cut off by friends
571 because of it when I've said, you know, this is what it
572 is, because I think, I believe, because they could kind of
573 go, oh, it's just [name of participant]. She's like, she's a
574 bit of funny sometimes, or she's a bit of an artist, and
575 that you know what they're like, like....I know. And
576 others who have gone all right? Yeah, that makes total
577 sense. Sorry, thought you were just being a bit of a
578 dick. (Laughter). So, yeah, I think people go one of
579 two ways.

580 I: And how do you kind of see it? You've talked about
581 this before?

582 P2: Yeah, I see it as a positive thing. Really, I mean
583 it's....and I don't think I fully appreciated how positive
584 it was until I actually did it, until actually I kind of
585 made myself go and get the diagnosis a few months
586 ago. But as soon as I did have it. It was just like, well,

*Diagnosis as a way of explaining
symptoms*

Better knowing than wondering

*Diagnosis as reference point
Diagnosis as freedom of naming the
problem*

*Diagnosis as providing common
experience and knowledge to relate to
Diagnosis as increasing knowledge of
self and own reactions
Diagnosis as being more honest with
self
Getting diagnosis as having more self
respect
Not having diagnosis as not dealing
with the problem
Diagnosis as increasing self-esteem
and feeling more independent*

587 anything that happens from here on, can't be as bad as
588 not knowing and it can't be as bad as wondering,

589 I: So what does knowing do? What's comfortable
590 about knowing?

591 P2: It's having just a concrete thing to refer back to.
592 And it's the freedom that goes with it. It's the freedom
593 of being able to say, this is something that I live with,
594 and I'm not just kind of amorphously a bit depressed or
595 not feeling right.

596 I: But there is something...a reason or something
597 behind it?

598 P2: Yeah. And there's a kind of...once you...and
599 obviously everybody experiences highs and lows
600 differently, and everybody experiences like....There
601 isn't one way to be bipolar, but you instantly have
602 access to kind of a whole bank of life experience that
603 other people had that you can relate to. And you get
604 that...that helps you kind of understand yourself and
605 your own reactions better. I think you just feel
606 like...well I feel like I've just being more honest with
607 myself. I have a lot more self-respect from having
608 done it, and having...because I think, as well, if you
609 haven't got diagnosis then you're probably not really
610 dealing with it. And it's made me deal with it, and it's
611 made me feel more...yeah it's made my self-esteem has

*Diagnosis as knowing what the
problem is*

Diagnosis as a point of reference

Diagnosis as understanding self

*Diagnosis as informative and
explanatory framework*

*Diagnosis as increasing knowledge of
own reactions*

Diagnosis as dealing with the problem

Diagnosis as dealing with the problem

612 got better (Laughter) and it's made me feel more kind
613 of independent.

614 I: Yeah. So you're independent. And where do you
615 think...so you're dealing with it. Do you feel a little bit
616 better in terms your self-esteem and independence? In
617 what other ways do you feel that you're dealing kind of
618 with it?

Taking medication

619 P2: It's practically, I've been taking medication
620 regularly for the first time, and I've committed to
621 having the therapy as well. And I keep a mood diary. I
622 talk about it a lot more openly. I feel much more able
623 to say...you know, I feel like I'm aiming a bit higher if
624 I feel like a bit low, or....And because I discuss it with
625 the people that I do kind of...that are supportive, it's
626 actually like I don't feel like I have to kind of make a
627 reason for faking out of something or feel bad about
628 that. I just have to say is "I'm not feeling very well,"
629 and that's it, and they get it and there's, that kind of
630 burden is off my shoulders and I know that kind...and I
631 know that I'm actually doing myself a favour.

Committing to therapy

632 I: And in terms of the medication, how was that kind of
633 discussed?

Meting psychiatrist as informative

634 P2: It was so really informative, again. I was really
635 grateful for that, because I think you know anybody
636 who's ever had any kind of depression would have
637 gone to the doctors and they would try to give them

*Importance of informatory and clear
information from doctor*

Options put clearly

Informative and collaborative

638 citalopram. After like a two minute conversation
639 (Laughter). And I...and when I first sought help again
640 and I just thought, oh god, like...it's always been one
641 of the things I struggle with, it's medication. But, yeah,
642 it was my options were kind of put to me very clearly,
643 and again it was...you know, it wasn't that I would just
644 take this and go away. It was, you know, you think
645 about it; you do your research. Here's all the possible
646 side effects. It was great.

647 I: It was very informative and collaborative.

648 P2: Very much so, yeah. And I feel...I felt much more,
649 I'm at ease and it's been amazing. (Laughter) Really.
650 (Overlapping Conversation).

651 I: Not being on it or, you know. And how....this may
652 be...so, kind of last, sort of thing or question.
653 How....What do you think the psychiatrist's kind of
654 main role for you then? And may be also what they
655 haven't done or could have done?

656 P2: Yeah. I think because...you know that you're the
657 first person that I really spoke to. That kind of meeting
658 and that discussion, it really set the tone for how am I
659 going to do for recovery, (Laughter) if you can call it
660 that, but then what I've done since, you know, had
661 definitely set the tone for that. And it was...it helped
662 me, because it was so, yeah, it was the first time I was
663 asked and I was, like, being completely open to

Non judgemental

Importance of speaking on even footing

Importance of exploring worries about potential stigma

664 anybody about my experiences, and....I think, it sounds
665 like such a cliché, but it was the fact that he wasn't
666 fazed by it (Laughter). And you were just saying "Oh,
667 yeah. Okay." But really open with me, like, didn't ask
668 me any leading questions and try and kind of put words
669 in my mouth, and you make positive, made it
670 practical....

671 I: Yeah.

672 P2: Yeah. Didn't speak to me like I was either
673 completely crazy or silly, which is good. So I think,
674 yeah. I think...I think you'd played a really important
675 role with that. I think, yeah, I don't really think there's
676 anything that could have been done at that stage. There
677 wasn't....

678 I: So you said may be something about....thinking
679 about the impact of it a bit, the label or maybe not at
680 that stage would you...

681 P2: Yeah. I think it's more like different people will
682 experience that differently, that you can't really
683 quantify it, can you? And I think generally, it's
684 something that's worth exploring with people because I
685 think bipolar is one of...I do genuinely, I get quite off
686 but I did done really think it's quite dangerous the way
687 it is spoken about in the media and kind of, in popular
688 culture because, you know, it's like a byword for crazy.
689 It's a get up clause. People think they can demonise

Importance of doctor being non-judgemental

Importance of equal relationship between client and clinician

[Type a quote from the document or the summary of an interesting point. You can position the text box anywhere in the document. Use the Text Box Tools tab to change the formatting of the pull quote text box.]

690 people with it by using it. And it is useful to kind of
691 get hands on, on how....

692 I: So some people don't know that it gives you some
693 sense of empowerment of perhaps in terms of, you
694 know, understanding how people might use that word
695 or....

696 P2: Yeah. Yeah. Definitely. And what people's
697 perceptions are. I just feel...It's just so ridiculous that
698 I...people would just not have anything to do with you
699 because of that (Laughter).

700 I: Because they're seen as mental as opposed to a
701 person.

702 P2: Yeah. Yeah. Pretty much.

703 I: Is there anything you think in terms of the experience
704 of diagnosis? Is there anything you think that maybe
705 we haven't talked about that you think might be
706 important? To think about or ask other people
707 (Laughter)?

708 P2: Sure. I was trying to think about what, everything
709 that I thought (Laughter) when it was going on.

710 I: Can you say more about your understanding and
711 experience and impact of it...medication.

[Type a quote from the document or the summary of an interesting point. You can position the text box anywhere in the document. Use the Text Box Tools tab to change the formatting of the pull quote text box.]

712 P2: I guess one thing that I found with people in a
713 similar situation to my own is that there's a real...like
714 some people just don't really know that there's
715 anything wrong with them. And there's an intervention
716 and they have to be kind of made to get diagnosis.
717 People are a little bit more like me when they think I
718 don't really wanna think about it (Laughter). But I
719 think people's reasons for seeking diagnosis are quite
720 diverse and it might be worth sort of asking people why
721 they did.

722 I: Yeah. Why did it sought to have it at all at all? Why
723 is it that...?

724 P2: Yeah.

725 I: Yeah. So a bit about maybe your own journey
726 where, in the beginning, you were more resistant to it,
727 and now maybe more willing to.

728 P2: Yeah. What, you want to know bit more about it?

729 I: Oh, no. I was just (Overlapping Conversation) if
730 your happy to (Overlapping Conversation).

731 P2: Yeah, yeah, yeah. So, I mean, I guess I can't a time
732 where I didn't experience anything about this. I've got
733 always, always....yeah, always kind of highs and lows.
734 I can't remember a time when I didn't believe really
735 deeply that there wasn't...that there was something

[Type a quote from the document or the summary of an interesting point. You can position the text box anywhere in the document. Use the Text Box Tools tab to change the formatting of the pull quote text box.]

736 wrong with me and I wasn't really a very nice person.
737 And so....and it was always kind of put to me from
738 kind of various sources that I...the way that I live and
739 the way that I experience the world wasn't right. So I
740 think that that kind of turn me away from seeking help
741 whenever I need it, actually, because...I just so
742 desperately wanted to be normal and to be, like....

743 I: So do you think that this does...there's a pressure
744 come from within or without?

745 P2: Both. But I think it's a really interesting kind of
746 nature nurture problem isn't it because I don't know. I
747 don't know if this is kind of something that you're born
748 with, or whether you learn it, or what. But...like, I do
749 know that yeah, I've never, never experienced it any
750 other way..

751 I: And was that discussed at all in the session?

752 P2: No, not so much. I think, you know...did we...I've
753 never even asked why I sought help. But I think with
754 bipolar interesting one because again there's this also
755 that thing I think that anybody who's ever had a high
756 completely fears, having that taken away and, yeah.
757 Okay, I definitely feel that. And that's....

758 I: But that part would go away?

*Importance of current mood on
experiences of usefulness of
diagnosis*

759 P2: Yeah. I haven't felt like I do when I'm high since
760 I've been taking medication. Yeah these are all reasons
761 why people just would and it's why people come off
762 meds because of it? Because they don't want to feel
763 held down.

764 I: But do you think...you think your view to you
765 diagnosis is differently depending on whether you feel
766 high or low or...?

767 P2: Yeah (Laughter). Yeah, confidently, I mean....

768 I: So would you think this interview would be very
769 different if you were other higher than to lower?

770 P2: Yeah.

771 I: Yeah.

772 P2: Yeah, definitely. I think, I mean if I...yeah, if I
773 were higher like I've been telling you that, you know,
774 diagnosis is really bad idea (Laughter). Because it push
775 you in a box and this is a gift and you know. Yeah, I
776 think sometimes...yeah, people get to a stage with the
777 highs where they are so destructive and I don't want or
778 the lows that they don't want to go on with it
779 (Laughter). That's my **_(49:15)_**

780 I: Yeah. Anything else we haven't talked about?
781 (Laughter).

*Current mood as influencing
experiences of receiving the diagnosis*

[Type a quote from the document or the summary of an interesting point. You can position the text box anywhere in the document. Use the Text Box Tools tab to change the formatting of the pull quote text box.]

782 P2: Everything is there (Laughter). That's right.

783 I: Thank you very much.

784 That's all

Appendix 7: Audit Trail

Chronological list of themes from interview 2

1. Not wanting anything to be wrong (27*)
2. Diagnosis as long term solution (48)
3. Upbringing influencing readiness to accept (63)
4. Diagnosis seen as failure (64)
5. Severity of symptoms influencing readiness to accept (72)
6. Importance of feeling on equal footing with doctor (89)
7. Importance of receiving unambiguous information (91)
8. Importance of collaborating between client and doctor (93)
9. Importance of working together to find treatment (96)
10. Importance of not feeling judged (110)
11. Importance of having practical focus (119)
12. Resisting diagnosis and questioning identity (149)
13. Diagnosis as long term solution (155)
14. Diagnosis as means to access to treatment (161)
15. Identifying with diagnosis sub-type (164)
16. Not identifying with mania (167)
17. Diagnosis as fitting experiences (175)
18. Diagnosis as fitting experiences (178)
19. Diagnosis as making sense (180)
20. Identifies with positive aspects of bipolar (186)
21. Not wanting to disclose diagnosis at work (207)
22. Worrying about being accepted (209)
23. Worrying about being perceived as dangerous (210)
24. Worrying having to change to manage symptoms (218)
25. Diagnosis as not being weak (249)
26. Diagnosis as becoming more companionate towards self (258)
27. Doing own research as gaining knowledge (274)
28. Importance of diagnosis fitting experiences (310)
29. Seeing diagnosis as sign of weakness (358)
30. Not feeling able to disclose (364)
31. Not being able to share diagnosis due to stigma (369)
32. Worries about stigma in society (384)
33. Bipolar seen a weakness (403)
34. Worries about stigma at work (445)
35. Diagnosis as means to planning for the future (458)
36. Worries about consequences of diagnosis on ability to work (467)
37. Worries about managing medication and wanting to have children (484)
38. Diagnosis as facing difficulties (500)
39. Diagnosis as having more agency (501)
40. Worrying about disclosure (531)
41. Worrying about being stigma as the most important thing (552)
42. Diagnosis as stigma and a way of explaining symptoms (576)
43. Diagnosis as knowing what the problem is (587)

44. Diagnosis as a point of reference (591)
45. Diagnosis as understanding self (598)
46. Diagnosis as informatory and explanatory framework (603)
47. Diagnosis as increasing knowledge of own reaction (605)
48. Diagnosis as facing the problems (607)
49. Importance of informatory and clear information from doctor (634)
50. Importance of doctor being non-judgemental (666)
51. Importance of equal relationship between client and clinician (672)
52. Current mood as influencing experience of receiving the diagnosis (776)

Clustered themes from interview 2

Theme 1: Diagnosis as access to treatment and long term solution

- Diagnosis as long term solution (48)
- Diagnosis as long term solution (155)
- Diagnosis as means to access to treatment (616)
- Diagnosis as means to planning for the future (458)
- Diagnosis as having more agency (501)

Theme 2: Diagnosis as failure

- Diagnosis seen as failure (64)
- Diagnosis as not being weak (249)
- Seeing diagnosis as sign of weakness (358)
- Bipolar seen a weakness (403)
- Not wanting anything to be wrong (27)

Theme 3: Importance of doctor patient relationship

- Importance of feeling on equal footing with doctor (89)
- Importance of receiving unambiguous information (91)
- Importance of collaborating between client and doctor (93)
- Importance of working together to find treatment (96)
- Importance of not feeling judged (110)
- Importance of having practical focus (119)
- Importance of informatory and clear information from doctor (634)
- Importance of doctor being non-judgemental (666)
- Importance of equal relationship between client and clinician (672)

Theme 4: Diagnosis as questioning identity

- Resisting diagnosis and questioning identity (149)
- Identifies with positive aspects of bipolar (186)
- Not identifying with mania (167)

Theme 5: Diagnosis as fitting

- Identifying with diagnosis sub-type (164)
- Diagnosis as fitting experiences (175)
- Diagnosis as fitting experiences (178)
- Importance of diagnosis fitting experiences (310)

Theme 6: Diagnosis as making sense

- Diagnosis as making sense (180)

Theme 7: Worry about disclosing and stigma

- Not wanting to disclose diagnosis at work (207)
- Worrying about being accepted (209)
- Worrying about being perceived as dangerous (210)
- Not feeling able to disclose (364)
- Not being able to share diagnosis due to stigma (369)
- Worries about stigma in society (384)
- Worries about stigma at work (445)
- Worrying about disclosure (531)
- Worrying about being stigma as the most important thing (552)
- Diagnosis as stigma and a way of explaining symptoms (576)

Theme 8: Diagnosis as facing difficulties

- Diagnosis as facing difficulties (500)
- Diagnosis as facing the problems (607)

Theme 9: Diagnosis as understanding self

- Diagnosis as understanding self (598)
- Diagnosis as informatory and explanatory framework (603)
- Diagnosis as increasing knowledge of own reaction (605)
- Diagnosis as knowing what the problem is (587)

Other themes:

- Diagnosis as becoming more companionate towards self (258)
- Doing own research as gaining knowledge (274)
- Worries about consequences of diagnosis on ability to work (467)
- Worries about managing medication and wanting to have children (484)
- Diagnosis as a point of reference (591)
- Current mood as influencing experience of receiving the diagnosis (776)
- Upbringing influencing readiness to accept (63)
- Severity of symptoms influencing readiness to accept (72)
- Worrying having to change to manage symptoms (218)

*Numbers in Brackets refer to the Line number from the interview

Service Evaluation Project

Evaluation of the School Change Day at the South Thames Cleft Service

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Abstract

The transition from primary to secondary school can be a challenging time for many children and their families. Among the challenges are changes in school environment, social interactions and academic expectations (Anderson et al., 2000). Additional difficulties may arise for children with a cleft lip and/or palate (CL/P). Research has shown that children with CL/P are more likely than their peers to experience teasing and bullying from other pupils, which can be very challenging and make the transition from primary to secondary school even more difficult (Lockhart, 2003; Rumsey, 2001). 'The School Change Day' at the South Thames Cleft Service (STCS) is a discussion and skills based one-day workshop based on the Outlook Summer Camp by Maddern and Owen (2004) and is designed to help children with CL/P negotiate the transition from primary to secondary school. The present study is an evaluation of the School Change Day. Data from 60 children and 60 parents/carers who attended the School Change Day between 2004 and 2010 was collected. Pre- and post-outcome measures (pre- and post-OMs) and anonymous feedback forms were administered to all participants. Results confirmed the transition to secondary school as a significant event, as demonstrated by the high prevalence of worry. Results also revealed specific additional concerns and worries for this population. However, a large proportion of the children employed healthy coping strategies in response to being teased. T-tests revealed that there were no significant differences between the children who had experienced teasing and those who had not in terms of how noticeable their cleft or how different their speech was as estimated by their parents. Further t-tests revealed that there were no significant gender differences in relation to 'self-reported happiness' and 'teasing related worries'. Overall, the day received high rates of satisfaction from both children and their parents, which suggests that a multifaceted intervention works well for this client group and age group. The evaluation also indicated that the children tended to enjoy activities with a behavioural focus more than those with a cognitive focus but tended to find the cognitive activities more useful than the behavioural ones. Limitations of the study are discussed and recommendations are made to the STCS, especially in relation to achieving better post-OM completion rates.

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1. Introduction

1.1. The Transition from Primary to Secondary School

The move from primary to secondary school is an important event for most children. It involves changes in the school environment, social interactions and academic expectations (Anderson et al., 2000) and adjusting to these changes can be anxiety provoking and difficult (Zeedijk et al., 2003). Although most children cope well (Brown et al., 2004), there is evidence that the primary-secondary school transition may affect some pupils negatively, exemplified by poorer school attendance, lower marks and an increase in challenging behaviours (Anderson et al., 2000). In addition, Marks (2004) found that there was a marked decrease in some children's well-being and happiness during the transition and a study by Wassell et al. (2007) found that pupils who could not cope with the new challenges of secondary school were at risk of becoming demotivated and potentially dropping out of school altogether. This has implications for pupils in terms of their future academic and personal development. West et al. (2008) found that maladjustment to secondary school can have a negative impact on pupils' psychological wellbeing and academic achievement beyond the school years. Thus, it follows from these studies that understanding the concerns and challenges facing children during the change from primary to secondary school is important in terms of helping them manage the transition and reduce the risk of maladjustment.

1.2. Common Transition Concerns

The main focus of the research into the primary-secondary school transition has been on pupils' subjective experience of changing school. Frequently reported concerns include bullying, adjusting to new school environments, getting lost, worries in relation to making friends, racist bullying, not fitting in, being the only child from their primary school, strict teachers, independence, increased responsibility and home work (Lucey & Reay, 2000; Ashton, 2008; Brown & Armstrong, 1982; Zeedijk et al., 2003). Brown and Armstrong (1982) found 22 different types of worries which they grouped into three categories: Interpersonal, Discipline and School Work. They also demonstrated that teachers' perception of the worries differed from those of the children, who tended to worry more about adjusting to increased work load and new rules than social issues. They argue that this discrepancy could have consequences for pastoral care aimed at facilitating a positive transfer. They suggest that pastoral care should focus more on supporting pupils in allowing them to make a more gradual transition from the two

learning environments (Brown and Armstrong, 1982). In contrast to Brown and Armstrong's (1982) study, Ashton (2008) found that the children in her study generally appeared to be more concerned about social aspects than academic aspects of the transition. However, most studies highlight the importance of supporting children with both academic and social challenges. In order to get a better understanding of the different types of transition worries and their prevalence, some researchers have begun to develop standardised and validated outcome measures, one of which will be considered in the next section.

1.3. Measuring Transition Concerns

One of the issues with the studies mentioned above is the lack of standardised outcome measures used to measure transition concerns and the lack agreement in terms of the terminology used to describe these experiences. Studies use a variety of different terms such as 'expectations', 'concerns', 'worries', 'perceptions', 'beliefs', 'feelings', and 'views'. The lack of standardised and validated outcome measures used in this area makes it difficult to compare studies and to draw any firm inferential conclusions regarding the usefulness of interventions. A study by Rice et al. (2010) has attempted to address this and examined the reliability and validity of the School Concerns Questionnaire (SCQ). The SCQ was developed by Thomasson et al. (2006). It is a self-report measure, which consists of 17 potential concerns about moving to secondary school (such as size of school, following a timetable, being bullied). Rice et al. (2010) found the SCQ to be a reliable and valid tool for assessing primary-secondary school transition concerns. As such, it could serve as a valuable tool in evaluating and developing school-based initiatives that aim to promote a positive secondary school transition. Parallel to this development, another line of research has attempted to shed light on the difficulties facing pupils during the school transition by drawing on theoretical models from life event research. This line of research has attempted to provide a coherent theoretical framework from which to conceptualize the transition.

1.4. A Conceptual Framework for Understanding the School Transition

Researchers have proposed different theoretical models to describe the primary-secondary school transfer. Barber (1999) suggested conceptualising the transition using a 'bridge' metaphor, in which five bridges are crossed all at the same time: bureaucratic, social and emotional, curriculum, pedagogy and management of learning. Sirsch (2003) suggested that the transition to secondary school could be understood as a complex,

normative life event as described by Filipp (1995a), involving a number of changes in the academic domain (i.e. new demands) and in the social domain (i.e. new teachers and classmates). Sirsch (2003) explored the transition further through Lazarus' cognitive-transactional stress theory (Lazarus, 1999). Here, the transition was seen as a potential stressful life event as described by Lazarus (1966). In his model stress is thought to occur as a function of the discrepancy between perceived demands of a situation and of the person's available resources for meeting those demands. As such, it is a person's appraisals of the situation and of their coping strategies which are central in determining whether or not a person experiences stress. Sirsch (2003) concluded that Lazarus' model provided a good explanatory framework for conceptualising the school transition. She pointed out that personal factors, in particular, seemed to influence whether or not a person perceived the school transition as a threat. In addition, very few students in this study perceived the transition from primary school to secondary school as both a low challenge and a low threat, which according to Sirsch (2003), confirms the transition as a significant and important life event for most of the children.

If the transfer to secondary school is viewed in this way, starting secondary school can be seen as an opportunity for change which may have positive as well as negative effects. A study by Lucey and Reya (2000) examined the way in which anxiety featured in the narratives of children moving from primary to secondary school. This study revealed that although many children expressed worry in relation to the move, there was also evidence to suggest that children were hopeful that the move would be manageable. Further clinical implications of Lazarus' model could be that interventions aimed at helping pupils through this transition should focus on changing cognitive appraisals and that evaluation of such interventions should include measures of cognitive appraisals as well as measures of worries and symptoms. Despite support for Lazarus model (such as Sirsch, 2003), it is still not clear which pupils are most likely to experience difficulties during the transition or what causes positive and negative appraisals. For most pupils, transition worries seem to be fairly brief and decrease throughout the first term of secondary school (Stradling & MacNeil, 2000). However, for some pupils the transition is not as straightforward. Studies into individual differences may provide some additional insight into why some students find this transition particular challenging.

1.5. Secondary School Transition and Individual differences

Studies have found individual differences in transition-related worries and adjustment (Wigfield et al., 1991; Graham & Hill, 2003; and Qualter et al., 2007), indicating that some pupils may be particularly vulnerable to adjustment difficulties during the primary-secondary school transition. A number of personal and demographic variables have been associated with poor transition with younger and less academically able pupils being less likely to adjust positively (Youngman, 1978). In addition, some studies have found that girls may be more vulnerable to transition worries (i.e. Anderson et al., 2000). However, the literature is inconsistent regarding gender differences with Wigfield et al. (1991) reporting reduction in self-esteem for both sexes following transition and Blyth et al. (1983) reporting reduction only for girls.

Another area of interest concerning individual differences is how pupils from ethnic minorities respond to the secondary school transfer. According to Graham and Hill (2003), pupils from minority ethnic backgrounds may experience more difficulties during school transition than children from a white British background. Graham and Hill (2003) argue that children from minority ethnic backgrounds may be particularly vulnerable because they often find themselves moving between and having to manage different cultural worlds at home and at school. Furthermore, teachers and schools vary in terms of how aware and respectful they are of cultural diversity and how much they understand the needs of children from minority ethnic backgrounds (Graham and Hill, 2003). The literature seems to suggest that both cognitive appraisals and individual differences may play a key part in how pupils adjust to the secondary school transfer. The next section will look at the research that has been carried out on the difficulties facing children with visible differences, and in particular children with a cleft lip and/or palate (CL/P), in relation to changing school.

1.6. The School Transition and Children with a CL/P and Visible Differences

For a child with a visible and/or speech difference, the transition to secondary school can be particularly difficult. In addition to the typical worries described above, these children may also experience worries relating specifically to their visible and/or speech difference. Although long-term psychiatric problems are uncommon for these children (Kleve and Robinson, 1999), psycho-social difficulties are widely reported. According to Lockhart (2003) and Rumsey (2001), 20-30% of children with CL/P experience clinically significant psycho-social difficulties. Research into the impact of living with a

visual difference has identified a wide range of psychological difficulties, particularly in the areas of social confidence and integration (Richman & Millard, 1997; Tobiasen, 1993), negative effects on self-concept (Leonard et al., 1991), behavioural problems (Kendall-Grove, et al., 1998) and low mood (Millard, 1996).

According to Robinson et al. (1996), children with CL/P are particularly vulnerable to experiencing emotional distress when starting secondary school. Robinson et al. (1996) argues that meeting new young people at secondary school is likely to result in more questions being asked, an increase in stares, and an increase in comments from their new peers, all of which can lead to increased distress. In addition, children who have experienced separation from parents and/or had traumatic experiences because of hospitalisation during their early childhood may find that these experiences exacerbate transition difficulties (Durkin, 2000). Furthermore, if a period of hospitalisation coincides with the transfer to secondary school, it can cause additional distress (Rodgers et al., 1994). At such times, psychological intervention may be particularly indicated to help these children and their families to cope with forthcoming changes and novel situations (Maddern & Owen, 2004).

1.7. Psychological Interventions for Children Experiencing Difficulties in Relation to Visible Differences

With regard to psychological interventions for children in general, a Cognitive-Behavioural Therapy (CBT) approach is widely regarded as providing a useful and beneficial treatment framework (Graham, 2000; Spence & Donovan, 2000). In addition, Ronen (1997) argued that a comprehensive understanding of the normal developmental processes is necessary to determine if specific behaviours are age appropriate or not. Furthermore, Spence et al. (2000) and Stallard (2002), suggest that interventions should be multi-dimensional, including problem-solving skills, relaxation skills, anxiety management skills, anger-control techniques, role plays, modelling and behavioural rehearsal. According to Dush et al. (1989), interventions tend to be more behavioural in nature for younger children (including techniques such as self-talk and rehearsal), whereas for adolescents, abstract cognitive strategies (such as changing automatic thoughts and cognitive restructuring) are used more frequently.

According to Newell and Marks (2000), the difficulties experienced by children with a visible difference can resemble those experiences by children with social anxiety and social phobia. Walters (1997) argues that children with a visible difference may worry more about how they come across (a key feature of social anxiety) and find it more difficult to be spontaneous in social situations. If this worry is not addressed it could, according to Walters (1997), instigate a vicious cycle of anticipatory worry, withdrawal and avoidance, resulting in a reduction of the number of opportunities to practise and develop social skills, which could have negative implications on the individual's self-concept (Harter, 1999).

Specific programmes and services have been developed to address psychological difficulties in children with a visible difference. Kapp-Simon and Simon (1991) developed a social skills training programme for adolescents with CL/P. They suggest focussing on five categories of skills: Social Initiation, Conversational Skills, Assertion or Direct Communication, Empathy or Active Listening and Conflict Resolution and Problem Solving. The Outlook Service within North Bristol NHS Trust has been developed for children, young people and adults with a different appearance. According to Achenbach (1991), the children seen in Outlook tend to score at the top end of the normal range for psychosomatic symptoms and anxiety, and generally do not have major family complications or social issues. Because these children are relatively high functioning, the majority of the work is focused on developing strategies for dealing with comments, teasing and bullying (Achenbach, 1991). Evaluation of the Outlook service suggests that children benefit in a number of ways. Results from a study carried out by (Maddern et al., 2006) evaluated the effectiveness of the Outlook service and found a significant decrease in the number of children teased at six months follow-up. In addition, significant reductions were also found in terms of somatic complaints and symptoms of depression and anxiety Maddern et al. (2006).

1.8. The Outlook Summer Camp: A School Transition Programme

The Outlook service also runs an annual Summer Camp. The Outlook Summer Camp is designed to help children with a visible difference to negotiate the challenges of starting secondary school. All children who have been referred to Outlook are offered to attend the Outlook Summer Camp when they reach their final year at primary school. The aim of the camp is to expand on the children's coping skills when faced with a social challenge. In addition to the children's group, a parallel parents' group is run, where

parents share their experiences and get an opportunity to hear about the strategies being taught to their children. An evaluation of the Outlook summer camp was carried out by Maddern and Owen (2004). Written and verbal feedback was obtained from both the children and their parents. Maddern and Owen (2004) concluded that the summer group provided a relatively easy and inexpensive intervention, which was seen as helpful by children and parents due to its normalising nature.

1.9. The School Change Day at the South Thames Cleft Service

The School Change Day is a one day workshop for children with CL/P, who are about to start secondary school. It is based on the Outlook Summer Camp by Maddern and Owen (2004) and is aimed at equipping the children with strategies and skills to deal with the transition in a positive way and equipping parents and carers with skills to enable them to support the children through this transition. The School Change Day at the takes place on an annual basis, either in the Easter holiday or in the May half-term break, before the children are due to start secondary school in the autumn. It is facilitated by a multidisciplinary team consisting of Clinical Psychologists, Speech and Language Therapists, Specialist Nurses and other professionals. The overall aim of the day was to enable the children to feel more positive about starting secondary school and to address anticipatory anxiety that may arise in relation to making this transition. Another aim was to enable the children to develop and practice strategies for integrating with a new social group and to help parents in supporting their child with this.

Two groups were run simultaneously - a children's group and a parents group. In the children's group, the children were encouraged to think about how they were feeling about starting secondary school and to think about other times when they have been in a new situation and how they managed. They were also encouraged to think about experiences of being teased and bullied and about how these experiences made them feel and how they coped in those situations. In addition, the children were taught problem-solving techniques to expand on their repertoire of responses to teasing and bullying. The children were also taught about body language and were encouraged to think about how body language could be an important strategy in responding to and preventing bullying. Role-play activities were also part of the workshop and provided the children with the opportunity to practice the techniques they have learned. Finally, fun games were used to both relax the children at the outset and to keep the energy going throughout the workshop.

In the parent group, parents and carers were encouraged to share their feelings and thoughts about their child starting secondary school. They were invited to share their experiences of dealing with difficult situations and to discuss what they could do to continue to support their child's transfer to secondary school. In addition, discussions were also had around how to support their child in using the strategies they have been taught during the workshop and to help their child to develop their own strategies for managing the secondary school transfer confidently (Please Appendix 1 and 2 for protocols of the two groups).

1.10. The Aim of this Service Evaluation

The overall aim of this service related project was to evaluate the School Change Day at The South Thames Cleft Service (STCS). In terms of hypotheses, it was expected that the majority of the children would express concerns and worries in relation to changing schools. It was also expected that the day would receive high overall ratings in line with findings from Maddern and Owen (2004) that the intervention would have a positive impact on 'teasing related worry'. The evaluation further aimed to explore if there were any gender differences in relation to teasing related worries and if experience of being teased was associated with severity of CL/P. Finally, behavioural and cognitive activities were compared for usefulness and helpfulness.

2. Method

2.1. Design and Materials

In order to evaluate the school change day, parents and children attending the group from 2004 to 2010 were asked to complete an anonymous feedback form (Appendix 5 and 6) in addition to filling in outcome measures (OMs) before and six months after the school Change Day (Appendices 3, 4, 7, and 8). The feedback forms were handed out at the end of the day in order to obtain feedback on the overall helpfulness and enjoyment of the workshop. Participants were asked to rate on a 10 point scale how helpful and enjoyable they found the day. In addition, participants were also asked to indicate the three activities they found most helpful and enjoyable and the activities they felt could have been left out. Finally, participants were asked how useful they felt it had been for them to meet children and parents in a similar situation to themselves and whether or not they wanted a shorter follow-up session after commencing secondary school. The

pre- and post-outcome questionnaires (Pre-OMs and Post-OMs) had been developed by clinicians within the STCS and were used to provide professionals with demographic information about the children attending the school change day (such as age, gender and leisure activities). These forms also included information regarding the children's levels of worry in relation to starting secondary school, what types of worries they had and how they have dealt with comments and teasing in relation to their CL/P.

2.2. Participants

In total, 60 children aged 11 or 12 (i.e. Year Six) with a diagnosis of CL/P and 60 parents/carers attended the School Change Day in seven consecutive years from 2004 to 2010. 40% of the children were girls. 60% of the children reported belonging to a social or sports club at school. The children reported engaging in a range of activities including playing computer games (28%), playing sports (75%) and singing (3.3%). In terms of self-reported sporting ability, 36.7% of the children rated themselves as average at sport, while 18.3% and 13.3% rated themselves as above and below average respectively. In terms of academic achievement, the ratings were similar, with 38.3% of the children rating themselves as average, while 18.3% and 13.3% of the children rate themselves as above and below average respectively (Please see Appendix 11 for participant demographics). It is not certain if these figures reflect norms in the general population, but the data appears to be normally distributed within this group.

2.3. Procedure for Data Collection and Analysis

When invited to attend the School Change Day, participants were asked to fill in the Pre-OM. At the end of each workshop participants were asked to fill in the anonymous feedback form and six month after the School Change Day, participants were sent the Post-OM. The variables selected for analysis were based on previous research findings from the literature and limited by completion rates and missing data.

3. Findings

3.1. Attendance and Completion Rates

Data was obtained from the seven School Change Day programmes in the period from 2004 to 2010. As seen in Table 1, a total of 60 young people and 60 parents attended the school change day in this period completing 57 (a completion rate of 95%) and 53 (a completion rate of 88%) anonymous feedback forms respectively. When looking at completion rates for Pre-OMs, these were lower with completion rates of 81% (49 completed) for the children and 73% (44 completed) for the parents. In terms of Post-OMs, completion rates were also lower. 21 out of the 60 children who attended completed Post-OMs (completion rate of 35%), whereas 20 out of 60 of the parents who attended completed the Post-OMs (completion rate of 33%) (Please see Appendix 10 for completion rates). One of the aims of the service evaluation was to carry out analysis comparing scores on Pre and Post-OMs to assist in evaluating the effectiveness of the School Change Day. However, due to the low completion rate of Post-OMs and complete datasets this has not been possible. As shown in table, there were no complete datasets in 2004, 2005 and 2009. In total, out of a possible 60, only 14 data sets were complete.

Table 1: Attendance and completed outcome and evaluation forms:

YEAR	Young Person				Parent				Complete Datasets
	Pre OM*	A*	E*	Post OM*	Pre OM	A	E	Post OM	
2004	6	6	5	0	6	6	6	0	0
2005	8	8	6	0	6	4	4	0	0
2006	11	11	11	5	8	14	14	5	5
2007	9	10	10	5	9	10	5	5	1
2008	8	12	12	5	8	10	10	4	3
2009	0	4	4	0	0	4	4	0	0
2010	7	9	9	6	11	12	10	6	5
Total	49	60	57	21	44	60	53	20	14

*Pre OM = Pre Outcome measure completed, A = Attended, E = Evaluation forms completed, Post OM = Post Outcome Measures

3.2. Pre-Post Comparisons

It has not been possible to carry out any inferential analysis, comparing Pre and Post-OMs, due to missing data. However, descriptive data is provided below on key variables (Appendix 12). When looking at percentages, the proportion of children being teased in secondary school compared to primary school, decreased from 63.5% to 18.2% (See Figure 1). Figure 1 also shows that there was a slight decrease, from 25.5% to 19%, in the amount of children using avoidance as a coping strategy.

Figure 1: Proportion of pupils teased and using avoidance as a coping strategy in primary and secondary school.

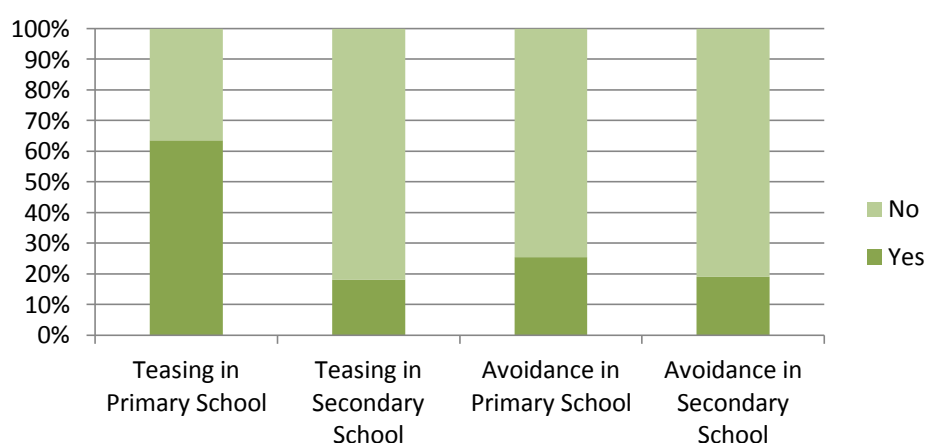
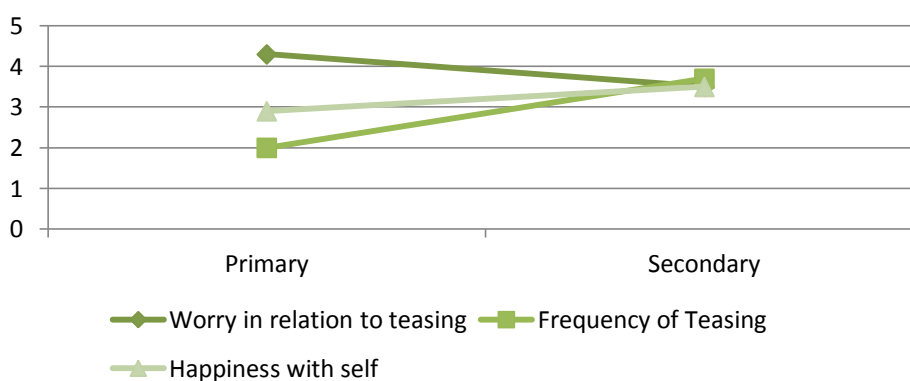


Figure 2 shows the amount of worry pupils experienced in relation to teasing, the frequency of teasing and the degree to which pupils were happy with themselves at primary and secondary school. Interestingly, in spite of there being a slight increase in the frequency of teasing in secondary school, the children were on average reporting more happiness and less worry in relation to teasing.

Figure 2: Mean worry in relation to teasing, frequency of teasing and happiness with self in primary and secondary school.



3.3. Sample Characteristics

3.3.1. Reported Concerns

63% of the children attending the school change day reported having concerns about starting secondary school. Table 3 provides an overview of the concerns reported by these children prior to attending the School Change Day. Of the 63% who reported concern in relation to starting secondary school, the most commonly endorsed concerns were, starting in a new school (20%), being picked on (14.3%), worries about what people think (14.3%), homework and school work (11.4%), operations (11.4%) and not having any friends (8.6%) (Please refer to Appendix 16).

Table 2: Type of transfer worries

Worry Type	N	%
Starting in a new School	7	20
Being Picked on	5	14.3
What people think	5	14.3
Homework and school work	4	11.4
Operations	4	11.4
Appearance	3	8.6
Not having friends	3	8.6
Speech	1	2.9
Sport	1	2.9
Being late	1	2.9
Getting into fights	1	2.9

The children were also asked if there were any situations in primary school they tended to avoid because of their CL/P. 20% of the children reported avoiding particular situations because of their cleft. Out of the total sample, 6.7% responded that they avoided socialising. Another 6.7% reported avoiding having their photo taken and 3.3% avoiding singing at school due to having CL/P.

3.3.2. Teasing and Coping.

55% of the children reported being teased in primary school (i.e. prior to attending the School Change Day). Out of this group, only 9% reported being teased ‘often’ or ‘very often’. 18% reported being teased ‘sometimes’ whereas 72% reported being ‘teased rarely’ or ‘very rarely’ in primary school. In coping with teasing at school, 29% of participants reported telling their teacher, 26% report responding to teasing by ignoring,

and 13% report getting angry and upset in response to being teased. Other responses included not telling anyone (6.5%), resorting to physical or verbal aggression (13%) or telling their parents (6.5%).

Using T-tests, to compare the children who had experienced teasing with those who had not, results revealed that there was no significant difference between the two groups in relation to how noticeable their cleft was ($t=-.280$, $df=43$, $p=.781$, two-tailed) or how different their speech was ($t=-.884$, $df=43.972$, $p=.382$, two-tailed) as estimated by their parents (See table 4). Equally, there was no significant difference between the two groups in terms of how well the parents believed their children were coping ($t=-.586$, $df=44$, $p=.561$, two-tailed). However parents of children who had reported that they had experienced teasing were more likely to report that they were not managing their child's CL/P well ($t=-3.087$, $df=27.741$, $p=.005$, two-tailed). It should be noted that Levene's test for equality revealed that there was no equality of variance between the two groups on when comparing noticeability of speech and parental management (please refer to Appendix 14).

Table 3: For all participants, the mean standard deviations (DV) for noticeability of cleft, estimated speech difference, coping with cleft and perceived parental management of child's cleft. For those Children who were teased and those children who were not teased, mean, Standard Deviations (SD) and t-tests for noticeability of cleft, estimated speech difference, coping with cleft and perceived parental management of child's cleft.

Variable	All participants		Teased in primary school		Not teased in primary school		t
	Mean	(S.D.)	Mean	(S.D.)	Mean	(S.D.)	
Noticeability of cleft	4.12	(3.44)	4.24	(3.61)	3.94	(3.24)	-.280
Estimated speech difference	4.78	(3.52)	5.09	(4.02)	4.21	(2.74)	-.884
Coping with cleft	8.59	(1.69)	8.72	(1.85)	8.42	(1.50)	-.586
Perceived parental management	8.04	(1.99)	8.80	(1.39)	7.00	(2.26)	-3.087

3.3.3. Questions, Comments and Responses.

58% of the children reported being asked questions about their CL/P at primary school. The majority (71.4%) of these questions were regarding facial appearance, whereas 28.6% of questions related to speech and language. Of the children who receive questions about their cleft, 36.1% reported feeling upset afterwards, 33.3% reported not 'being bothered' and 19.5% reported feeling angry or annoyed. In terms of reactions, 71.4% offered an explanation in response to questions asked. Other responses included being assertive (8.6%), ignoring (8.6%), walking away (5.7%), denying (2.9%) or doing nothing (2.9%) (please refer to Appendix 17)

3.3.4. Gender differences

Research has suggested that girls may be more likely to be negatively affected by transition worries. When comparing the two genders in this sample, boys on average reported more worry in relation to teasing than girls (Table 5). The mean(SD) for boys on teasing related worry was 4.82(2.46) whereas for girls, mean(SD) was 3.67(2.97). However, boys on average also reported higher levels of happiness with self with a mean(SD) of 3.04(1.26) compared to girls where the mean(SD) was 2.89(1.1). T-tests revealed that there were no significant differences between the two genders on teasing related worry ($t=1.285$, $df=35$, $p=.207$, two-tailed) and happiness with self ($t=.395$, $df=45$, $p=.694$, two-tailed) (please refer to Appendix 18).

Table 4: For boys and girls, mean, Standard Deviations (SD) and t-tests for teasing related worry and happiness with self.

Variable	Boys		Girls		t
	Mean	S.D.	Mean	S.D.	
Teasing related worry	4.82	(2.46)	3.67	(2.97)	1.285
Happiness with Self	3.04	(1.26)	2.89	(1.1)	.395

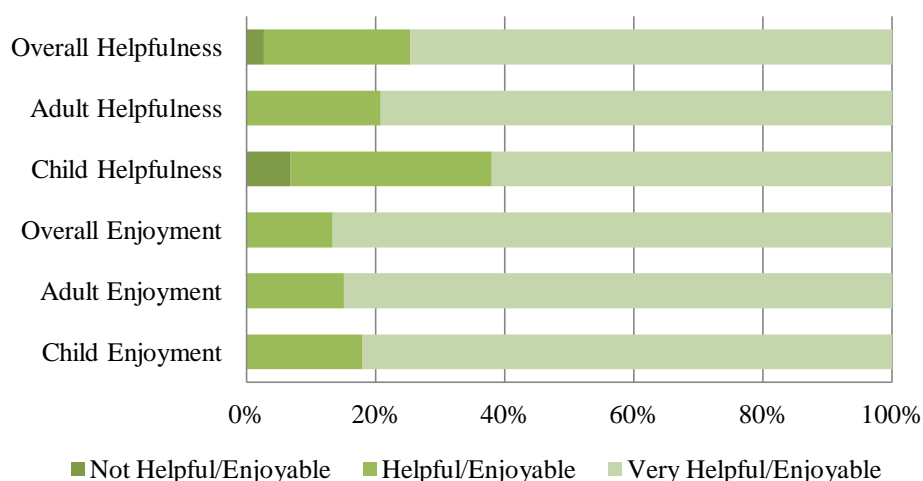
3.4. On the Day Evaluation of the School Change Day

Anonymous feedback forms were obtained on the day from the children and their parents. As mentioned above, overall completion rates were high at 95% for the children and 88% for the parents, mainly because these forms were anonymous and completed on the day.

3.4.1 Overall Enjoyment and Helpfulness of the day

Figure 3 provides an overview of the enjoyment and helpfulness rating provided by the children and their parents. In terms of how helpful the children had found the day, the majority (62%) gave the day a rating of ‘very helpful’, rating it as eight, nine or 10 out of 10. In terms of enjoyment, more than 80% of the children gave this rating. On average adults found the day slightly more helpful when compared to the children, with almost 80% of adults rating the day ‘very helpful’. In terms of enjoyment 84.8% of parents gave the day a rating of eight, nine or 10 out of 10 (Please refer to Appendix 15).

Figure 3: Overall, Adult and Child Helpfulness and Enjoyment ratings.



3.4.2. Most and Least Enjoyable and Helpful Activities

Enjoyment and helpfulness ratings for each activity are shown in table 6. In terms of which activities the children enjoyed the most, the three highest ratings were ‘the shopping basket game’ (50.9%), ‘the hat game’ (49.1%) and ‘the noticing game’ (42.1%). The three children’s activities that were rated most helpful were ‘the group discussion’ (61.4%), ‘the brainstorm about making friends’ (42.1%) and the ‘brainstorm about managing new situations’ (38.6%). In terms of the least helpful or enjoyable activity, 26.3% of the children felt that the Line-up game could have been ‘missed out’. In terms of which activities the parents enjoyed the most, the three highest rating were ‘the group discussion’ (77.4%), ‘discussion about helping the child cope’ (73.6%) and ‘practical strategies’ (62.3%). These three activities also rated highest in terms

helpfulness, with 86.8% of parents rating ‘the discussion about helping the child to cope’ among the most helpful activities, 84.9% favouring ‘the group discussion’ and 69.8% preferring ‘the strategies’. There were no activities that were seen as being unhelpful by more than 7.5% of the parents in the group.

Table 5: Most and Least Enjoyable and Helpful Activities

Most and least Enjoyable and Helpful activities in percent						
Activity	Child most enjoy	Child most helpful	Child miss out	Parent most enjoy	Parent most helpful	Parent miss out
Child Activities						
Welcome activity	17.5%	10.5%	8.8%	24.5%	13.2%	3.8%
Warm up game	26.3%	5.3%	10.5%	-	-	-
Group Discussion	17.5%	61.4%	5.3%	-	-	-
Shopping Basket Game	50.9%	1.8%	5.3%	-	-	-
Noticing game	42.1%	28.1%	5.3%	-	-	-
Brainstorm new situations	5.3%	38.6%	3.5%	-	-	-
Hat Game	49.1%	33.3%	7.0%	-	-	-
Line-up Game	35.1%	12.3%	26.3%	-	-	-
Brainstorm Making friends	21.1%	42.1%	1.8%	-	-	-
Praising Self Esteem game	31.6%	19.3%	8.8%	-	-	-
Adult activities						
Introduction activity	-	-	-	24.5%	24.5%	7.5%
Group Discussion	-	-	-	77.4%	84.9%	3.8%
Own Experiences	-	-	-	22.6%	22.6%	3.8%
Helping child to cope	-	-	-	73.6%	86.8%	1.9%
Strategies	-	-	-	62.3%	69.8%	0.0%
Final thoughts	-	-	-	7.5%	9.4%	3.8%

3.4.3. The Relationship between Helpfulness and Enjoyment.

The relationship between perceived helpfulness and enjoyment of activities was explored using Pearson’s correlations. In the children’s group there was a significant but ‘weak’ positive correlation between ratings of enjoyment and helpfulness of the different activities ($r = .471$, $N=56$, $p=.000$). In the parents’ group there was also a significant positive correlation between rating of helpfulness and enjoyment of activities ($r = .635$, $N=53$, $p=.000$). However, the association between helpfulness and enjoyment were stronger in the parents’ group than in the children’s group, as the correlation in the parents’ group was considered to be of ‘moderate’ strength (please refer to Appendix 15).

3.4.4. Feedback on having a Follow-up Group

Finally, all participants were asked if they wanted a follow-up group after commencing secondary school. Out of 102 responders, 85.3% said 'yes' to having a follow-up group while 14.7% said 'no'. Of the 87 participants who said 'yes' to a follow-up group, 49.4% preferred to have the follow-up group in the Autumn half-term, while 25.3% and 14.9% opted for the Christmas holidays and Spring half-term respectively. In addition, 47.1% of participants who answered 'yes' to having a follow-up group wanted this group to be organised for both children and their parents, while 4.6% felt the follow-up group should be for the children only. 48.3% of people who wanted a follow-up group did not answer this question (please refer to Appendix 9).

4. Discussion

The transfer to secondary school is generally viewed as a key life stage for most children and may be particularly challenging for children with CL/P. The main aim of this study was to evaluate the usefulness and helpfulness of the School Change Day run by the STCS and to provide clinicians with information regarding the children attending the day. The STCS School Change Day was adapted from the Outlook Summer Camp by Maddern and Owen (2004) and designed to support children with CL/P who were about to start secondary school by providing a forum in which they and their parents were encouraged to share their experiences, concerns, and coping strategies.

4.1. Reported Concerns

Before attending the STCS School Change Day, 63% of the children reported having concerns about starting secondary school, which confirms the transition as a significant event as proposed by a number of researchers (Sirsch, (2003); Anderson et al, 2000; Zeedijk et al., 2003). Among the most commonly endorsed concerns were starting in a new school (20%), being picked on (14.3%), increased academic demands (11.4%) and not having any friends (8.6%). These concerns echo findings by Anderson et al. (2000), who argued that the main challenges facing children when changing to secondary school lie in three different domains: school environment, social interactions and academic expectations. Findings also correspond with research by Lucey and Reay (2000), Zeedijk et al. (2003) and Ashton (2008). Furthermore, in line with Ashton (2008), findings from this study indicate that children may be more concerned with social aspects than academic aspects of the transition, with only 11.4% reporting worries in terms of increased academic demands. Finally, some specific additional worries seem to

be present for the children in this study compared to the studies mentioned above. These involve worries about how other pupils will view them (14.3%) and worries about operations (11.4%). These findings suggest that some children with CL/P may experience additional worries and concerns, which may complicate the transition further as pointed out by (Rodgers et al., 1994). This has implications in terms of developing interview schedules or standardised outcome measures aimed at examining the structure of transition concerns or evaluating the effectiveness of an intervention aimed at children with CL/P who are about to change school. It is likely that such measures would benefit from including CL/P specific concerns about visible or speech difference.

4.2. Teasing and Coping.

55% of the children who attended the school change day reported being teased in primary school. Out of this group, 28% reported being teased 'sometimes', 'often' or 'very often'. These figures echo findings by Lockhart (2003) and Rumsey (2001) that a significant amount of children in the CL/P population experience psychological difficulties due to teasing. To explore potential reasons for the high level of teasing in this client group, this study compared children who had experienced teasing with those who had not in terms of how noticeable their CL/P was and how different their speech was as estimated by their parents. Findings from this study revealed that there were not differences between the two groups on these variables, which support findings by Robinson et al., (1996) who found that children's confidence and social skills were more important than the type or severity of their cleft, in terms of coping with teasing and bullying.

In addition to experience teasing, 58% of the children also reported being asked questions about their CL/P at primary school. The majority (71.4%) of these questions were in relation to facial appearance whereas 28.6% of questions related to speech and language. This again highlights the additional potential for stress during the school transition as questions are likely to increase when meeting new people as pointed out by Robinson et al. (1996). Again, the fact that 36.1% of the children who were asked questions about their cleft, reported feeling upset afterwards, echo Lockhart (2003) and Folkman (2001) who both highlight the significance of this event and potential for additional stress.

In coping with teasing at primary school, more than half of the children in this study reported ‘telling their teacher’ or ‘ignoring’ as a coping response. This indicates that a large proportion of these children have developed healthy and appropriate coping responses prior to attending the School Change Day. This study also revealed that, in coping with teasing, the children used a range of responses and although most responses were appropriate, a significant minority (19.5%) had resorted to less helpful strategies such as getting angry, or resorting to verbal and/or physical aggression. Perhaps the potential for success of these types of interventions and the high levels of satisfaction lies in the opportunity for the children and their parents to share experiences, allowing those children who are not coping well to learn from other children and to develop new more helpful strategies. Diversity within group therapy is, according to Spence et al. (2000) and Stallard (2002), a key factor in terms of seeing improvements in individual group members.

4.3. Gender Differences

As mentioned, some studies have found girls to be more vulnerable to transition worries (i.e. Anderson et al., 2000). This study did not find any gender differences in relation to ‘teasing related worry’. One reason for this could be that the children in this client group were generally well prepared for dealing with teasing as illustrated by the high proportion of children in this study employing adaptive coping skills. Preparedness, among other variables (such as Socio-economic status (SES), behavioural problems and academic achievement) is, according to Anderson et al. (2000), a key determinant of a successful transition. Equally there were no differences between the sexes in terms of ‘happiness with self’, which support findings by Wigfield et al. (1991).

4.4. Evaluation

Anonymous feedback forms were given out at the end of the School Change Day, which resulted in very high completion rates. In line with findings from Maddern and Owen (2004), both children and parents reported high levels of satisfaction, with 62% of the children and 80% of the adults finding the day ‘very helpful’ and 80% of the children and 84.8% of the adults finding the day ‘very enjoyable’. In addition, 85.3% of participants said ‘yes’ to having a follow-up group, which also suggests high levels of satisfaction. Having a follow-up group may also have the added benefit of improving completion rates on post-OMs.

In terms of which activities the children enjoyed the most, the three highest rating were ‘the shopping basket game’, ‘the hat game’ and ‘the noticing game’. These are all fun games, which puts emphasis on behavioural components such as role-plays and rehearsal. However the three activities the children rated as *most helpful* were ‘the group discussion’, ‘the brainstorm about making friends’ and ‘the brainstorm about managing new situations’. All these activities place more emphasis on cognition. These findings indicate that this age group may benefit from behavioural strategies as well as cognitive strategies. This is also in line with (Spence et al., 2000; Stallard, 2002), who recommend that interventions should be multifaceted. In terms of which activities the parents enjoyed the most, the three highest rating were ‘the group discussion’, ‘discussion about helping the child cope’ and ‘practical strategies’. These three activities also rated highest in terms of helpfulness.

Although there was generally a high degree of satisfaction with most activities, a quarter of the children felt that the Line-up game (see Appendix 1 for a description) could have been ‘missed out’. Although this game was intended to get children talking about difference and normalising difference, it may not have had this effect. As argued by Newell and Marks (2000), the difficulties experienced by children with a facial difference resembles social anxiety and social phobia. It is possible that some of the children in this study may have felt that this exercise was too exposing or challenging and thus preferred not to have it as part of the group. Following from this line of thought, arguments can be had both ways in terms of whether or not to leave this activity out of the group altogether. An initial reaction might be to leave it to avoid children feeling uncomfortable. Another option may be to keep it in and perhaps spend more time on debriefing after the activity and address the feelings brought on by this activity. In this way the activity may be seen as more useful and less threatening.

Finally, the relationship between ‘usefulness’ and ‘enjoyment’ was examined and found to be stronger in the parents group than in the children’s group. Although no directional relationship can be postulated, a possible explanation could be that in order for the parents to enjoy these types of interventions, they must also consider them to be helpful. Whereas the children may have enjoyed some activities in spite of not finding them equally helpful, on the other hand may have found some activities helpful without enjoying them particularly. Again, most of the literature suggests using a multi-

component approach, incorporating cognitive, behavioural and experiential techniques for this age-group (Spence et al., 2000; Stallard, 2002).

4.5. Limitations

The main limitation of this study is the poor completion rate on post-OMs, which has rendered it impossible to carry out any inferential pre-post analysis and thus made it difficult to compare this intervention with other similar initiatives. Collecting the post-OM data has been difficult as not all children were seen regularly in the service. One solution to this could be to have a brief follow-up group (which 85.3% of participants said 'yes' to), which is likely to increase completion rates for post OMs. Another limitation of this study is the lack of validated outcome measures used. This also renders it difficult to draw firm conclusions about effectiveness or when comparing it with other studies.

5. Conclusion and Recommendations

The STCS School Change Day was designed to support children with CL/P through helping them to share experiences, concerns, and coping strategies. For the parents, a parallel group was run to help them tackle feelings of worry and anxiety and to help them in supporting their children throughout their transition to secondary school. The School Change Day provides a relatively straight forward intervention, which is seen as helpful and enjoyable for the children and their parents alike. It provides an alternative to individual interventions and it helps the children feel better about the transition by normalising the difficulties they are experiencing by introducing them to other people with similar experiences. The high satisfaction rates across the different activities indicate that the day is very useful and enjoyable for both children and parents. Results suggest that adopting a multifaceted cognitive-behavioural approach for this client group is beneficial.

Based on this evaluation, a number of recommendations have been made to the STCS: First of all, it might be useful to use more standardised outcome measures such as the ones used in similar interventions like the Strength and Difficulties Questionnaire (SDQ) or the School Concerns Questionnaire (SCQ). However it is worth considering adding further questions relating specifically to issues experienced by children with CL/P such as self-image, noticeability of cleft and speech, self-perception and perception of difference. Adding standardised measures used in other interventions

would enable the service to compare the school change day directly with other similar programmes. In order to evaluate if the service is making a difference to the children a key question is: 'what is it the service is hoping to change for the participants?' and following from that: 'how can this be measured?'

Secondly, it might be worth considering changing the protocol in order to improve response rate for post-OMs. Having a good response rate post intervention is vital, regardless of the choice of measures used. At the moment the children and their parents are sent the post-OMs. Another option could be to use an online survey that does not require participants to post anything back. Perhaps calling people, completing the post-OMs via phone interviews could also be useful. In addition, most participants felt it would be useful to have a follow up group and this could also be an opportunity to obtain post data.

Thirdly, it might be worth considering the potential for confounding variables. Even with validated outcome measures and good response rates it may be difficult to determine whether or not any change on outcome measures are due to the intervention or the change of environment (i.e. changing from primary to secondary school) or maturation and personal development. There are a number of ways to get around this. One option would be to set up a Randomised Controlled Trial (RCT), where children are randomly selected to attend the school change day. However, incorporating a control group poses an ethical dilemma as the service may end up providing an effective intervention to some children and not others. From previous groups, there have been a number of children who do not attend due to other commitments, which could potentially be used as a control group. Another option could be to include a variable that captures the degree to which a young person is happy or satisfied with their current school, both pre- and post-intervention. It is then possible to control for any variance that the change of school might have on other outcome variables.

Finally, findings from this study would suggest leaving out the Line-up game or perhaps change the way it is carried out. Results also indicate that parents as well as children would like to have a follow-up group and that the preferred time for this group should be in the autumn half-term.

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Appendix 1: Protocol for the Children's Group

10.30-10.45 Welcome activity with the parents

Everyone is sat in a circle and staff and participants introduce themselves to the group. Each person is asked to say their name, where they have travelled from today and where they would like to go for their summer holiday. This activity is meant to serve as an ice breaker and as a way for everyone to start to get to know the other people in the group. After the introductions the group is split into a children's group and a parents' group.

10.45-11.00 People Bingo

In this ice breaker activity, each child has a bingo sheet with a number of statements. Each person has to get names of other members of the group who are in agreement with these statements. The aim is to get the children to interact with each other and get to know each other.

11.00-11.15 Group discussion regarding worries about secondary school

For this activity, the children are split into 3 or 4 groups and asked, in their small groups, to think about how they are feeling about starting secondary school and to write each feeling down on a sticky label. If the children find it difficult to generate any responses, time is spent on talking about what feelings are and a given examples of different kind of feelings. After a brief discussion each sub-group is asked to feedback to the larger group and at the end of the activity each person is asked to select a word that best sums up how they are feeling about starting secondary school.

11.15-11.25 The Line up game

The Line-up game is designed to normalise difference and facilitate communication between the children. The children are asked to form a line in terms of who has the least or the most of what is being asked. For example, children may be asked to form a line in terms of who is oldest or tallest or who has the darkest hair. Eventually the children might be asked about who has had the most operations or scars or other things that relate to their CLP.

11.25-12.00 Noticing Game

In this game the children leave the room in turns and change something about their experience. When they return to the room the other children have to try to spot the difference. The children are encouraged to make the changes subtle. The group often struggle to spot the changes, which teaches them that even when a group of people actively tries to spot a difference, this can be very difficult. Often little difference (such as a scar) is not noticed in real life. (Needs rephrasing).

12.00-12.30 Brainstorm – Coping in new situations and dealing with teasing

The children are asked to think about other situations where they have had to do something new and how they coped with this. In small groups the children are encouraged to think about what could have helped make those situation easier. If the children find it difficult to generate scenarios, the facilitator in each group will give an example of their own. The ideas generated in each subgroup are fed back to the larger group.

1.30-1.35 Hat Game

The hat game is a fun game that teaches children to respond to different comments and questions using a range of different strategies and techniques such as using humour, assertiveness and ignoring. The children are asked if they have any worries when they start secondary school in terms of coming across people who may be unkind or say unkind things. All the children pair up and take it in turns to wear a silly hat while the other person makes an unkind comments about the hat (the children are specifically asked only to comment on the hat).

1.35-2.00 Making Friends

Role play and body language

Dolphins, fish and sharks (making friends).

Using the metaphor of the underwater playground, in which small fishes (passive), schools of dolphins (assertive) and sharks (aggressive) play the familiar playground characters, the child is encouraged to find ways to be 'more like a dolphin': sociable, friendly and supportive to their friends. The children role-play making friends; for example, making an approach, listening to a conversation, joining in, asking questions and joining in a game. Dealing with teasing (seeing off the sharks). Fogging = assertive = being 'more like a dolphin'. Children learn to counteract namecalling by using a string of blocking words: 'so ... whatever ... boring ... absolutely ... yeah, yeah, yeah'. This is role played with puppets: each child experiences the victim and bully perspective and the difference between a passive and an assertive response. Other solutions explored include using humour and knowing when and how to ignore provocation and to ask adults for help.

2.00-2.25 Group Fun Activity - One in the middle and guess who you are

A fun game that gets the energy flowing. The children sit in a circle and swap chairs as their fruit is called. Fruit salad has everyone on their feet swapping chairs.

2.20-2.40 Self-esteem Game

In turn each person is praised by the group. Other group member are asked to raise their hand if they have something nice to say about the person in question and the person in question will chose from the other people who they would like to receive a comment from. (rephrasing).

2.40-3.00 Feedback with Parents

The children feed back to the parent about the different activities and what they have learnt during the day.

Appendix 2: Protocol for the Parents' Group

10.30-10.45 Welcome activities with the children

(Described above in the protocol for the children's group)

11.00-11.30 Sharing feelings and thoughts about their child starting secondary school

Initially parents introduce themselves and describe their child. It is left to them how much they share about their child's condition. This is followed by an open discussion about the children moving on to secondary school.

11.30-12.00 Dealing with new situations positively

The parents share their experience about what has been helpful in overcoming difficulties in the past. Normalising the experience of having a child changing school is important, together with practical advice about who to contact at the school if there are any concerns.

1.15-1.45 What to do to support their children's transfer to secondary school

Parents are given information and resources for themselves, their child and the school. The parents' group has become more important and longer year by year and now feels as important and significant as the children's group.

1.45-2.30 How to support their child to develop their own skills and strategies to manage the secondary school transfer confidently

2.40-3.00 Feedback session with the Children

(Described above)

Appendix 3: Pre Outcome Measure for the Children

QUESTIONNAIRE FOR SCHOOL CHANGE DAY

1 Name

.....

2 How old are you?

.....

3 Which school are you at?

4 Have you been teased or called names since you have been there?

.....

How often does this happen?

.....

What do you do when it happens?

.....

How much does it worry you?

Does not worry
me at all

Worries me a
great deal

0 1 2 3 4 5 6 7 8 9 10

5 Do people ask you questions about your appearance/speech?

Yes/No

If yes:

- What do they ask?

.....
.....

- How do you feel when they ask?

.....
.....

- What do you say/do?

.....
.....

6 Are there any things that you avoid because of your appearance/speech?

Yes/No

If yes, what do you avoid?

(e.g. going to parties, going to the park, having photos taken?)

.....
.....
.....
.....

7 How often do you worry about things?

Always
Often
Sometimes
Never

If you worry, what sort of things do you worry about?

.....
.....
.....

8 What about friends-some kids would like to have more friends, others have more than they want. How about you?

I would like to have a lot more friends
I would like to have a few more friends
I have enough friends
I have too many friends (if yes, is this a problem?)

.....

9 Do you belong to any clubs?

Yes/No

If yes, which clubs to you belong to?

.....
.....

10 What do you like doing in your spare time?

- 1
- 2
- 3
- 4

Compared to other people, how good are you at the first thing on the list above?

Above average
Average
Below average
Don't know

11 Do you play any sports?

If yes, what sport(s) do you play?

- 1
- 2
- 3
- 4

Compared to other people, how good are you at sports?

Above average
Average
Below average
Don't know

12 Compared to other kids, how good are you at schoolwork?

- Above average
- Average
- Below average
- Don't know

13 Some kids are happy being the way they are, others wish they could be different in some way. How do you feel?

- I am happy the way I am
- I am quite happy
- I am not particularly happy or unhappy
- I am unhappy the way I am
- I am very unhappy the way I am

If unhappy, what would you like to be different?

.....

.....

.....

.....

Thank you very much for taking the time to fill in this questionnaire.

Appendix 4: Pre Outcome Measure for the Parents

QUESTIONNAIRE FOR SCHOOL CHANGE DAY - PARENTS

1 Name of Child

.....

2 Child's DOB

.....

3 Current School

.....

4 Any concerns at current school?.....

.....

.....

5 Does your child have any special needs/speech or learning difficulties?

.....

.....

.....

6. What treatment has your child received for their cleft lip and/or palate? Is any treatment due to take place soon?

.....

.....

.....

7. How satisfied are you with the treatment?

.....

.....

8. How satisfied are you with the results of treatment?

.....

.....

Parent Rating Scales:

1. How noticeable do you feel your child's cleft is now to other people?

a) Overall appearance: (Please mark on line)

Not at all noticeable Very noticeable

0 1 2 3 4 5 6 7 8 9 10

b) Speech:

Not at all noticeable Very noticeable

0 1 2 3 4 5 6 7 8 9 10

2. How happy do you feel your child is at the moment?

a) With his/her facial appearance:

Very unhappy Very happy

0 1 2 3 4 5 6 7 8 9 10

b) With his/her speech:

Very unhappy

Very happy

0 1 2 3 4 5 6 7 8 9 10

3. How much do you think the cleft affects your child's interactions with other people?

Not at all

A Great Deal

0 1 2 3 4 5 6 7 8 9 10

4. Overall, how well do you feel your child copes with his/her cleft?

Does not cope at all

Copes very well

0 1 2 3 4 5 6 7 8 9 10

5. Overall, how well do you feel you manage any concerns your child has about his/her cleft?

Not very well

Very well

0 1 2 3 4 5 6 7 8 9 10

Please specify if there are any concerns you would like some help with?

.....
.....

.....
.....

7. Are there any specific questions or concerns you have related to your child starting secondary school?

.....
.....
.....
.....
.....
.....
.....

Thank you very much for taking the time to fill in this questionnaire.

Appendix 5: Anonymous Feedback Forms for the Children

EVALUATION FOR SCHOOL CHANGE DAY Young Person's questionnaire																					
<p>1) How enjoyable did you find today? (Please mark on the line)</p> <div style="display: flex; justify-content: space-between; align-items: center;"> Not at all enjoyable Very enjoyable </div> <div style="text-align: center; margin-top: 5px;"> 0 1 2 3 4 5 6 7 8 9 10 </div>																					
<p>2) What group activities did you enjoy most? (Please tick up to three)</p> <table style="width: 100%; border-collapse: collapse;"> <tbody> <tr><td>Welcome activities</td><td style="text-align: center;">☹️</td></tr> <tr><td>Warm up game</td><td style="text-align: center;">☹️</td></tr> <tr><td>Group discussion – "Secondary School"</td><td style="text-align: center;">☹️</td></tr> <tr><td>Shopping basket game</td><td style="text-align: center;">☹️</td></tr> <tr><td>Noticing games</td><td style="text-align: center;">☹️</td></tr> <tr><td>Brainstorm – "New Situations"</td><td style="text-align: center;">☹️</td></tr> <tr><td>The Hat Game</td><td style="text-align: center;">☹️</td></tr> <tr><td>Line-up Game</td><td style="text-align: center;">☹️</td></tr> <tr><td>Brainstorm – "Making Friends"</td><td style="text-align: center;">☹️</td></tr> <tr><td>Praising game</td><td style="text-align: center;">☹️</td></tr> </tbody> </table>		Welcome activities	☹️	Warm up game	☹️	Group discussion – "Secondary School"	☹️	Shopping basket game	☹️	Noticing games	☹️	Brainstorm – "New Situations"	☹️	The Hat Game	☹️	Line-up Game	☹️	Brainstorm – "Making Friends"	☹️	Praising game	☹️
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The Hat Game	☹️																				
Line-up Game	☹️																				
Brainstorm – "Making Friends"	☹️																				
Praising game	☹️																				

5) Did you find it useful to meet other young people with a cleft?

Not at all useful

Very useful

0 1 2 3 4 5 6 7 8 9 10

6) Is there any activity you think we could miss out if we were to run a similar group for young people starting secondary school next year? (Please tick).

Welcome activities	<input type="checkbox"/>
Warm up game	<input type="checkbox"/>
Group discussion – "Secondary School"	<input type="checkbox"/>
Shopping basket game	<input type="checkbox"/>
Noticing games	<input type="checkbox"/>
Brainstorm – "New Situations"	<input type="checkbox"/>
The Hat Game	<input type="checkbox"/>
Line-up Game	<input type="checkbox"/>
Brainstorm – "Making Friends"	<input type="checkbox"/>
Praising game	<input type="checkbox"/>

7) Do you have any suggestions on how to improve the day?

.....

.....

.....

.....

7) Would you be interested in a shorter follow-up group, once you have started secondary school?

Yes/No (Please circle one)

If yes – would you like the group to take place: (Please tick one)

In the October half-term ☐ Christmas holidays ☐

Other (Please specify) ☐

Thank you completing this form

Appendix 6: Anonymous Feedback Forms for the Parents

<u>EVALUATION FOR SCHOOL CHANGE DAY</u> Parent's questionnaire	
1) How enjoyable did you find today? (Please mark on the line)	
Not at all enjoyable	Very enjoyable
0 1 2 3 4 5 6 7 8 9 10	
2) What group activities did you enjoy most? (Please tick up to three)	
Welcome activities with children	<input type="checkbox"/>
Parent introductory activities	<input type="checkbox"/>
Group discussion – "Worries and concerns"	<input type="checkbox"/>
'Own experiences of new situations'	<input type="checkbox"/>
'Helping your child cope with new situations'	<input type="checkbox"/>
'Strategies for managing comments and questions'	<input type="checkbox"/>
Final Thoughts	<input type="checkbox"/>
3) How helpful did you find today? (Please mark on the line)	
Not at all helpful	Very helpful
0 1 2 3 4 5 6 7 8 9 10	
4) What group activities did you find most the most helpful? (Please tick up to three)	
Welcome activities with children	<input type="checkbox"/>
Parent introductory activities	<input type="checkbox"/>
Group discussion – "Worries and concerns"	<input type="checkbox"/>
'Own experiences of new situations'	<input type="checkbox"/>
'Helping your child cope with new situations'	<input type="checkbox"/>
'Strategies for managing comments and questions'	<input type="checkbox"/>
Final Thoughts	<input type="checkbox"/>

5) Did you find it useful to meet other parents of young people with a cleft?

Not at all useful

Very useful

0 1 2 3 4 5 6 7 8 9 10

6) Is there any activity you think we could miss out if we were to run a similar group for parents next year? (Please tick).

Welcome activities with children	<input type="checkbox"/>
Parent introductory activities	<input type="checkbox"/>
Group discussion – "Worries and concerns"	<input type="checkbox"/>
'Own experiences of new situations'	<input type="checkbox"/>
'Helping your child cope with new situations'	<input type="checkbox"/>
'Strategies for managing comments and questions'	<input type="checkbox"/>
Final Thoughts	<input type="checkbox"/>

7) Do you have any suggestions on how to improve the day?

.....

.....

.....

.....

8) Would you be interested in a shorter follow-up group, once your child has started secondary school? Yes/No (Please circle one)

If yes – would you like the group to take place: (Please tick one)

In the October half-term ☐ Christmas holidays ☐

Other (Please specify) ☐

And do you think the follow-up group should be: (Please tick one)

For young people only ☐ Parents and young people ☐

Thank you completing this form

Appendix 7: Post Outcome Measure for the Children

QUESTIONNAIRE FOR SCHOOL CHANGE DAY

1 Name

.....

2 How old are you?

.....

3 Which school are you at?

4 Have you been teased or called names since you have been there?

.....

If yes:

- How often does this happen?

.....

- What do you do when it happens?

.....

- How much does it worry you? Please circle:

Does not worry
me at all

Worries me a
great deal

0 1 2 3 4 5 6 7 8 9 10

5 How much are you enjoying secondary school? Please circle:

Not at all

A great deal

0 1 2 3 4 5 6 7 8 9 10

6 Do people ask you questions about your appearance/speech?

Yes/No

If yes:

- What do they ask?

.....

.....

- How do you feel when they ask?

.....

.....

- What do you say/do?

.....

.....

7 Are there any things that you avoid because of your appearance/speech?

Yes/No

If yes, what do you avoid?

(e.g. going to parties, going to the park, having photos taken?)

.....

.....

.....

.....

8 How often do you worry about things?

- Always
- Often
- Sometimes
- Never

If you worry, what sort of things do you worry about?

.....

.....

.....

9 What about friends-some kids would like to have more friends, others have more than they want. How about you?

- I would like to have a lot more friends
- I would like to have a few more friends
- I have enough friends
- I have too many friends (if yes, is this a problem?)

.....

10 Do you belong to any clubs?

Yes/No

If yes, which clubs to you belong to?

.....

.....

11 What do you like doing in your spare time?

- 1
- 2
- 3
- 4

Compared to other people, how good are you at the first thing on the list above?

Above average
Average
Below average
Don't know

12 Do you play any sports?

If yes, what sport(s) do you play?

- 1
- 2
- 3
- 4

Compared to other people, how good are you at sports?

Above average
Average
Below average
Don't know

13 Compared to other kids, how good are you at schoolwork?

- Above average
- Average
- Below average
- Don't know

14 Some kids are happy being the way they are, others wish they could be different in some way. How do you feel?

- I am happy the way I am
- I am quite happy
- I am not particularly happy or unhappy
- I am unhappy the way I am
- I am very unhappy the way I am

If unhappy, what would you like to be different?

.....

.....

.....

.....

Thank you very much for taking the time to fill in this questionnaire.

Appendix 8: Post Outcome Measure for the Parents

QUESTIONNAIRE FOR SCHOOL CHANGE DAY - PARENTS

1 Name of Child

.....

2 Child's DOB

.....

3 Current School

.....

4 Any concerns at current school?

.....

.....

.....

.....

5 Does your child have any special needs/speech or learning difficulties?

.....

.....

.....

**6 How well do you feel your child has settled into secondary school?
Please circle:**

Not at all settled

Very settled

0 1 2 3 4 5 6 7 8 9 10

Thank you very much for taking the time to fill in this questionnaire.

Appendix 9: Follow-up Group (SPPS)

Table 19a: Frequency table in relation to having a follow-up group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	87	79.1	85.3	85.3
	No	15	13.6	14.7	100.0
	Total	102	92.7	100.0	
Missing	999.00	8	7.3		
Total		110	100.0		

Table 19b: Frequency in relation to when to have follow-up group

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Autumn Half Term	43	49.4	49.4	49.4
	Christmas Holidays	22	25.3	25.3	74.7
	Spring Half Term	13	14.9	14.9	89.7
	999.00	9	10.3	10.3	100.0
	Total	87	100.0	100.0	

Table 19c: Frequency in relation to having a follow-up group only for children

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Children only	4	4.6	4.6	4.6
	Both Adults and Children	41	47.1	47.1	51.7
	999.00	42	48.3	48.3	100.0
	Total	87	100.0	100.0	

Appendix 10: Attendance and Completion Rates (SPSS)

Table 10a: Number of children attending the school change day from 2004-2010

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2004.00	6	10.0	10.0	10.0
	2005.00	8	13.3	13.3	23.3
	2006.00	11	18.3	18.3	41.7
	2007.00	10	16.7	16.7	58.3
	2008.00	12	20.0	20.0	78.3
	2009.00	4	6.7	6.7	85.0
	2010.00	9	15.0	15.0	100.0
	Total	60	100.0	100.0	

Table 10b: Number of parents attending the school change day from 2004-2010

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2004.00	6	10.0	10.0	10.0
	2005.00	4	6.7	6.7	16.7
	2006.00	14	23.3	23.3	40.0
	2007.00	10	16.7	16.7	56.7
	2008.00	10	16.7	16.7	73.3
	2009.00	4	6.7	6.7	80.0
	2010.00	12	20.0	20.0	100.0
	Total	60	100.0	100.0	

Table 10c: Child Completion of Pre Questionnaire

		Child Completion of Pre OM		Total
		No	Yes	
Year	2004	0	6	6
	2005	0	8	8
	2006	0	11	11
	2007	1	9	10
	2008	4	8	12
	2009	4	0	4
	2010	2	7	9
Total		11	49	60

Table 10d: Adult Completion of Pre Questionnaire

		Adult Completion of Pre OM		Total
		No	Yes	
Year	2004	0	6	6
	2005	2	6	8
	2006	3	8	11
	2007	1	9	10
	2008	4	8	12
	2009	4	0	4
	2010	2	7	9
Total		16	44	60

Table 10e Child Completion of Post Questionnaire

		Child Completion of Post OM		Total
		No	Yes	
Year	2004	6	0	6
	2005	8	0	8
	2006	6	5	11
	2007	5	5	10
	2008	7	5	12
	2009	4	0	4
	2010	3	6	9
Total		39	21	60

Table 10f: Adult Completion of Post Questionnaire

		Adult Completion of Post OM		Total
		No	Yes	
Year	2004	6	0	6
	2005	8	0	8
	2006	6	5	11
	2007	5	5	10
	2008	8	4	12
	2009	4	0	4
	2010	3	6	9
Total		40	20	60

Table 10g: Complete Data Set

		Complete Data Set		Total
		No	Yes	
Year	2004	6	0	6
	2005	8	0	8
	2006	6	5	11
	2007	9	1	10
	2008	9	3	12
	2009	4	0	4
	2010	4	5	9
Total		46	14	60

Table 10h: Child and Adult Completion of Evaluation Form

		Child or Adult		Total
		Child	Adult	
Year	2004	5	6	11
	2005	6	4	10
	2006	11	14	25
	2007	10	5	15
	2008	12	10	22
	2009	4	4	8
	2010	9	10	19
Total		57	53	110

Appendix 11: Participant Demographics (SPSS)

Table 11a: Gender of Child

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	36	60.0	60.0	60.0
	Female	24	40.0	40.0	100.0
	Total	60	100.0	100.0	

Table 11b: Percentage of children belonging to a club

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	10	16.7	21.7	21.7
	Yes	36	60.0	78.3	100.0
	Total	46	76.7	100.0	
Missing	999.00	14	23.3		
Total		60	100.0		

Table 11c Spare time activities

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Computer Games	17	28.3	37.0	37.0
	Drawing	3	5.0	6.5	43.5
	Read	6	10.0	13.0	56.5
	Playing	8	13.3	17.4	73.9
	Sport	8	13.3	17.4	91.3
	Singing and Playing music	2	3.3	4.3	95.7
	Being with Family	1	1.7	2.2	97.8
	Watch TV	1	1.7	2.2	100.0
	Total	46	76.7	100.0	
Missing	999.00	14	23.3		
Total		60	100.0		

Table 11d: Type of sport

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Football	14	23.3	31.1	31.1
	Netball	5	8.3	11.1	42.2
	Rounders	3	5.0	6.7	48.9
	Running	1	1.7	2.2	51.1
	Cricket	1	1.7	2.2	53.3
	Hockey	3	5.0	6.7	60.0
	Martial Arts	3	5.0	6.7	66.7
	Tennis	4	6.7	8.9	75.6
	Baskey Ball	3	5.0	6.7	82.2
	Swimming	3	5.0	6.7	88.9
	Gymnastics	2	3.3	4.4	93.3
	Ice Skating	1	1.7	2.2	95.6
	Darts	1	1.7	2.2	97.8
	Golf	1	1.7	2.2	100.0
	Total	45	75.0	100.0	
Missing	999.00	15	25.0		
Total		60	100.0		

Table 11e: Sport ability rating

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Below Average	8	13.3	19.0	19.0
	Average	22	36.7	52.4	71.4
	Above Average	11	18.3	26.2	97.6
	3.00	1	1.7	2.4	100.0
	Total	42	70.0	100.0	
Missing	999.00	18	30.0		
Total		60	100.0		

Table 11f: School work ability rating

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Below Average	8	13.3	19.0	19.0
	Average	23	38.3	54.8	73.8
	Above Average	11	18.3	26.2	100.0
	Total	42	70.0	100.0	
Missing	999.00	17	28.3		
	System	1	1.7		
	Total	18	30.0		
Total		60	100.0		

Appendix 12: Pre-Post Descriptive Comparisons (SPSS)

Table 12a: Teasing in Primary School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	19	31.7	36.5	36.5
	Yes	33	55.0	63.5	100.0
	Total	52	86.7	100.0	
Missing	999.00	8	13.3		
Total		60	100.0		

Table 12b: Teasing in Secondary school

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	18	30.0	81.8	81.8
	Yes	4	6.7	18.2	100.0
	Total	22	36.7	100.0	
Missing	999.00	38	63.3		
Total		60	100.0		

Table 12c: Use of avoidance as a coping strategy in Primary school

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	35	58.3	74.5	74.5
	Yes	12	20.0	25.5	100.0
	Total	47	78.3	100.0	
Missing	999.00	13	21.7		
Total		60	100.0		

Table 12d: Use of avoidance as a coping strategy in primary School

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	17	28.3	81.0	81.0
	Yes	4	6.7	19.0	100.0
	Total	21	35.0	100.0	
Missing	999.00	39	65.0		
Total		60	100.0		

Table 12e: Mean scores of teasing related worry in primary and secondary school

	N	Mean	Std. Deviation	Std. Error Mean
Worry in relation to teasing	37	4.3514	2.69996	.44387
Secondary teasing worry	9	3.5556	3.53946	1.17982

Table 12f: Mean scores of frequency of teasing in primary and secondary school

	N	Mean	Std. Deviation	Std. Error Mean
Frequency of teasing in Primary School	32	2.0313	1.06208	.18775
Secondary teasing frequency	4	3.7500	1.50000	.75000

Table 12g: Mean scores of happiness with self in primary and secondary school

	N	Mean	Std. Deviation	Std. Error Mean
Happiness with Self	47	2.9787	1.18852	.17336
SecondarySelfHappiness	21	3.4762	1.03049	.22487

Appendix 13: Assumption Checks on Key Variables

1. Missing data

Missing data was dealt with through list-wise deletion. This was deemed acceptable as the missing data appeared to occur randomly across the data-set

2. Outliers

Stem-and-leaf-plots were used to identify possible outliers across the main variables.

Figure 13.1: Stem-and-leaf plot for Noticeability of Cleft

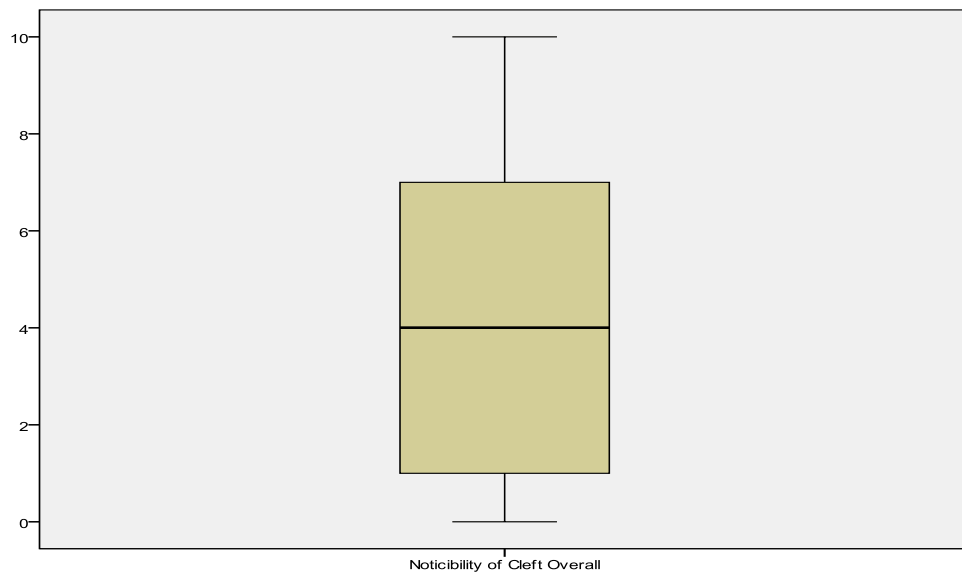


Figure 13.2: Stem-and-leaf plot for Noticeability of Speech

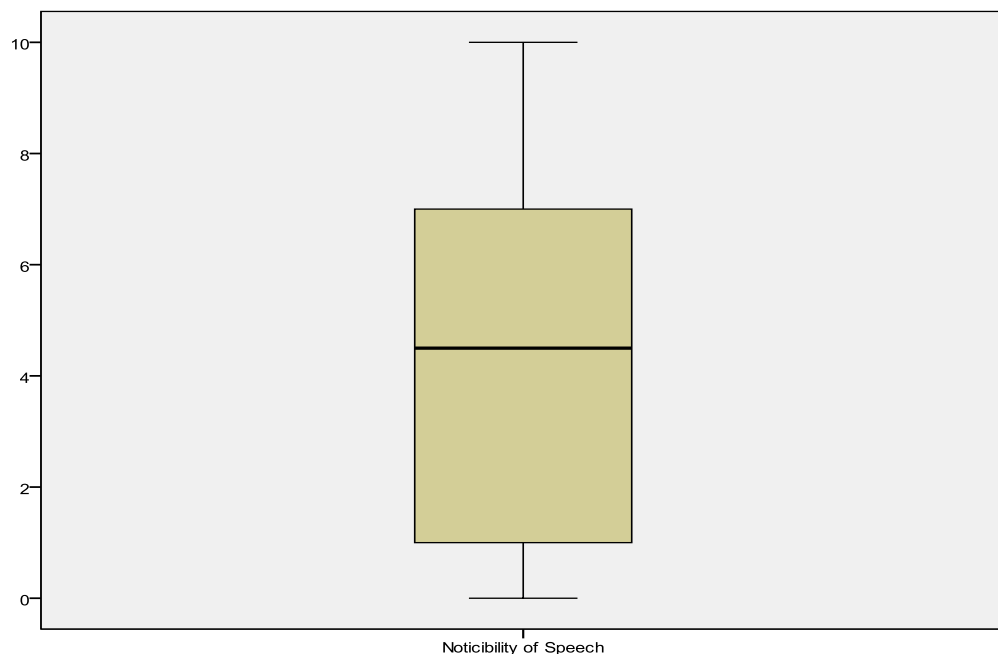


Figure 13.3: Stem-and-leaf plot for Parent Estimation of Coping in Primary School



Figure 13.4: Stem-and-leaf plot for Parental Management of Cleft



Figure 13.5: Stem-and-leaf plot for Worry in Relation to Teasing

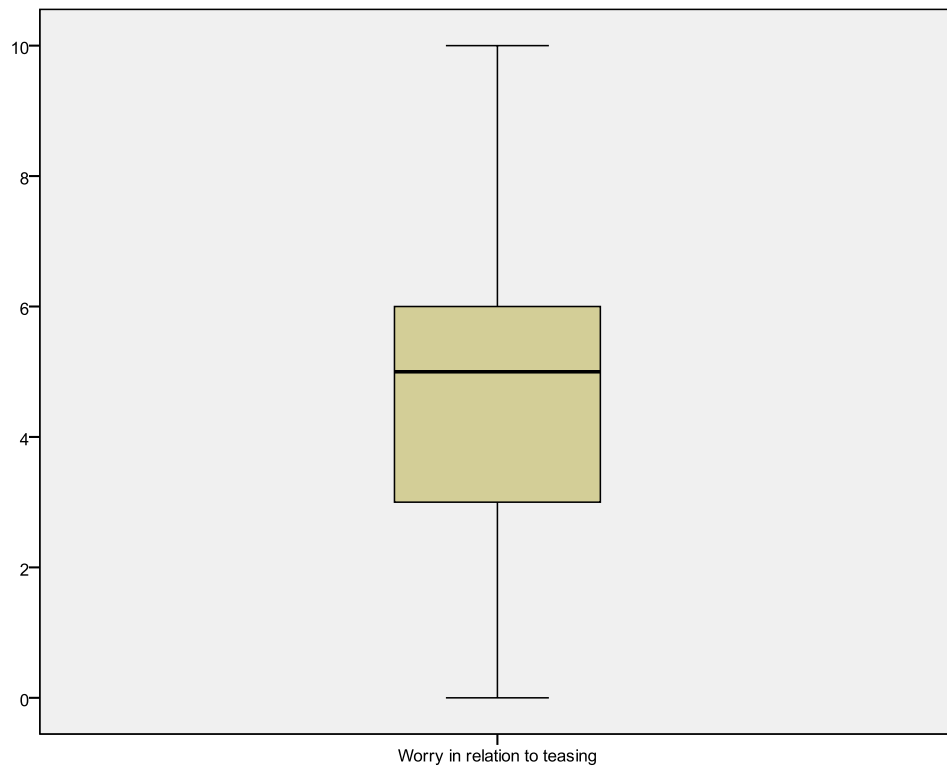


Figure 13.6: Stem-and-leaf plot for Happiness with Self

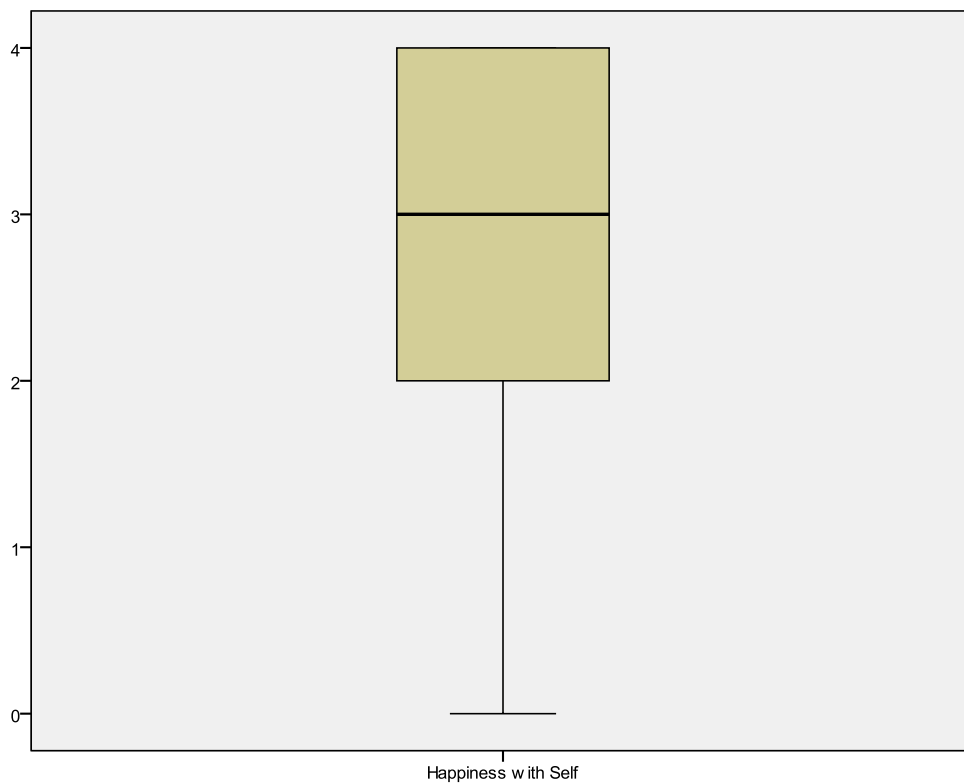


Figure 13.7: Stem-and-leaf plot for overall Child Enjoyment

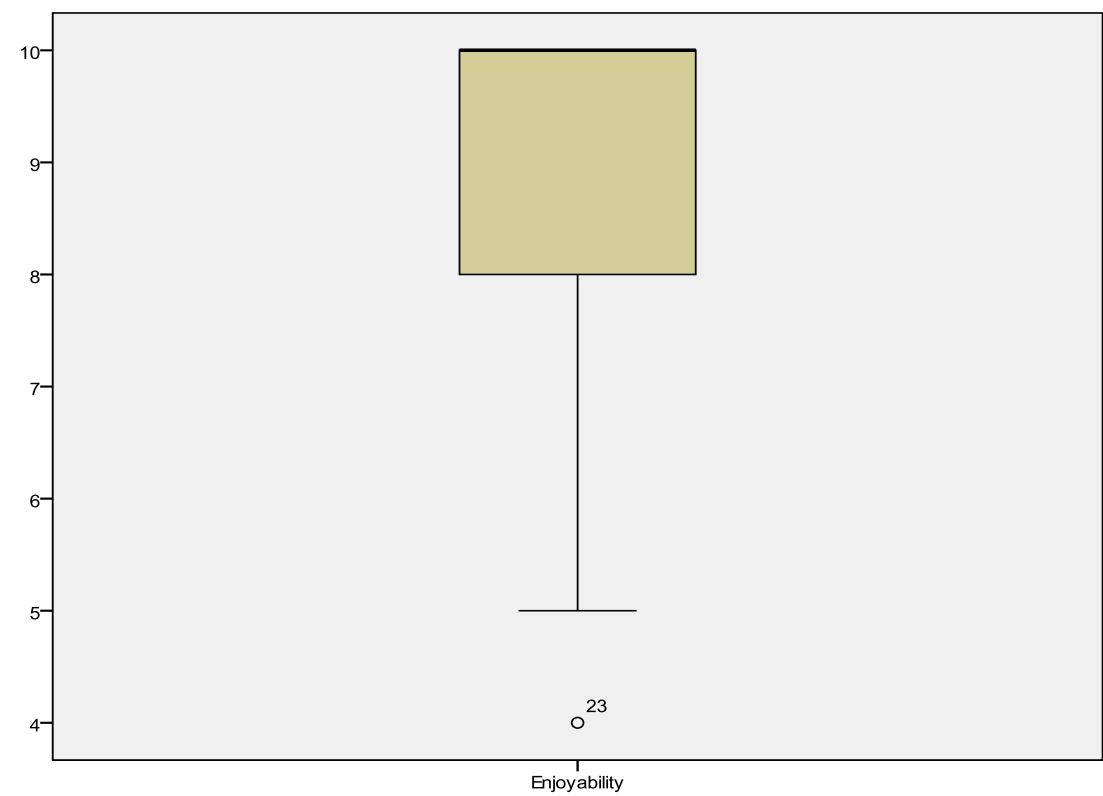
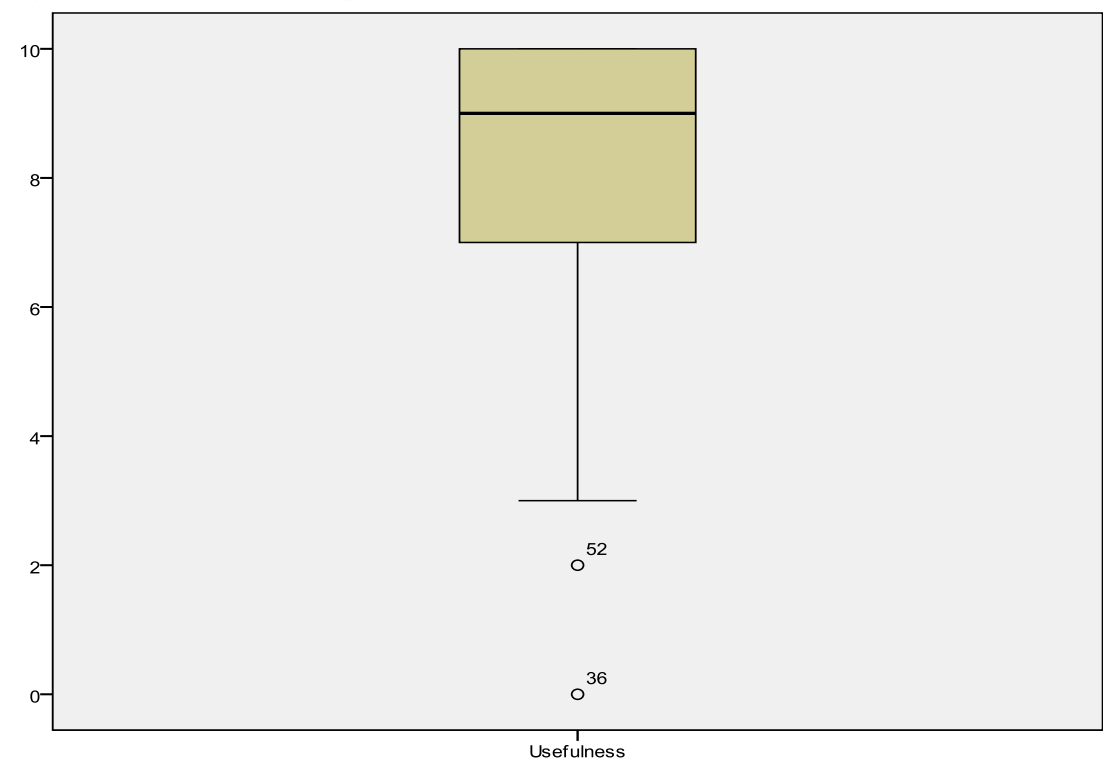


Figure 13.8: Stem-and-leaf plot for overall Child Usefulness



6. Normality

Normality: P-P Plots

P-P plots were used to check for normal distribution of main variables. The further away the dots are from the line (The expected score), the more likely it is that the variables has out-liers and is not normally distributed.

Figure 13.9: P-P Plot of Noticeability of Cleft Overall

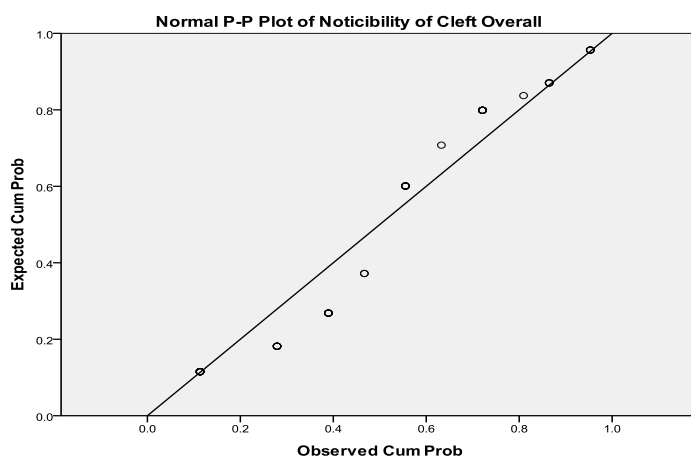


Figure 13.10: P-P Plot of Noticeability of Speech

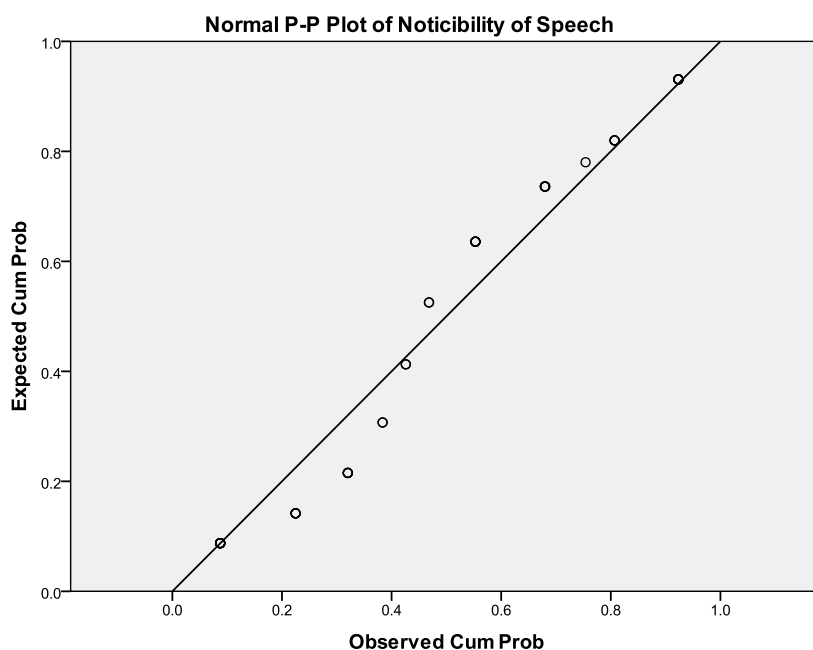


Figure 13.11: P-P Plot of Parental Estimation of Coping in Primary School

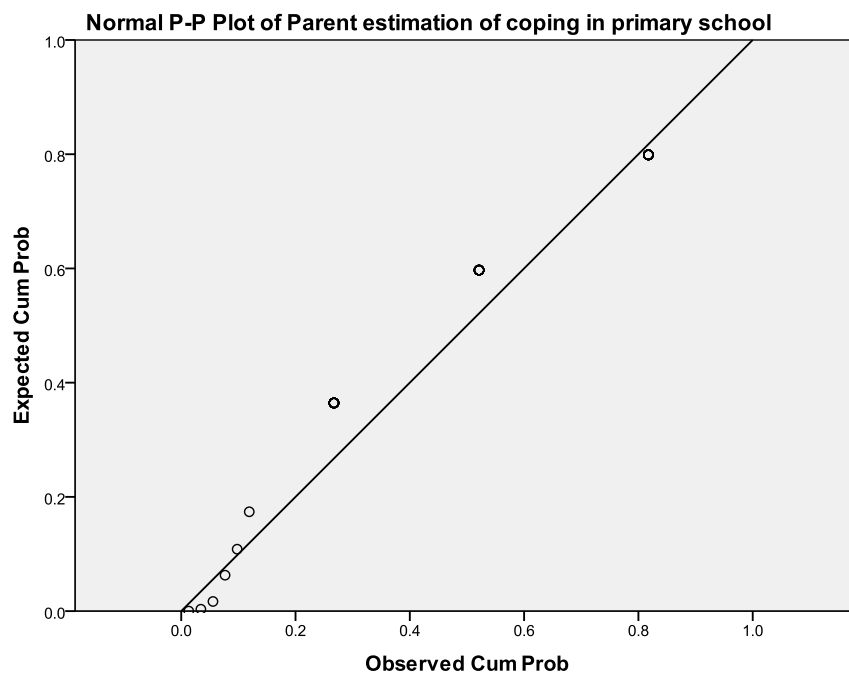


Figure 13.12: P-P Plot of Parental Management of Cleft

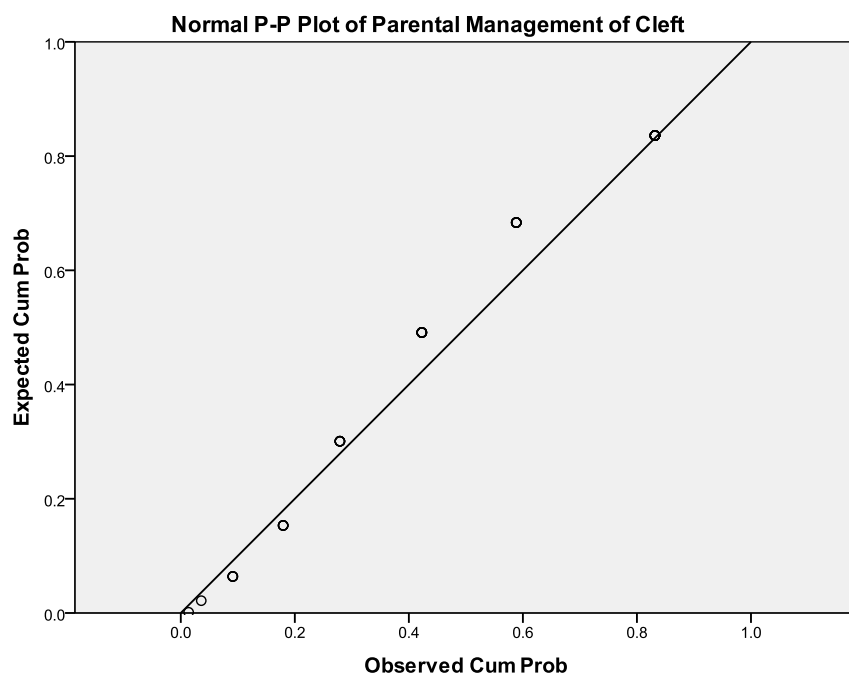


Figure 13.13: P-P Plot of Worry in relation to Teasing

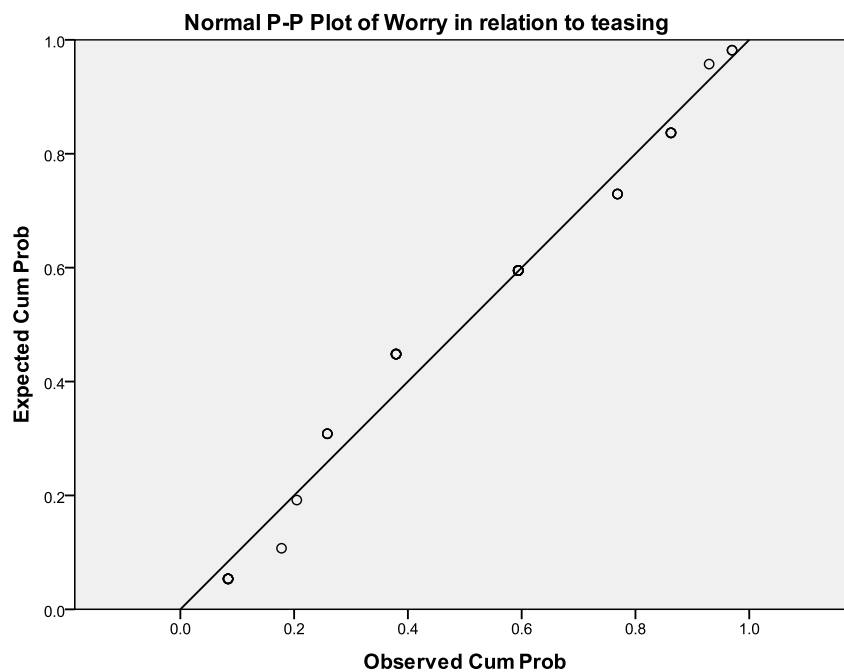


Figure 13.14: P-P Plot of Happiness with Self

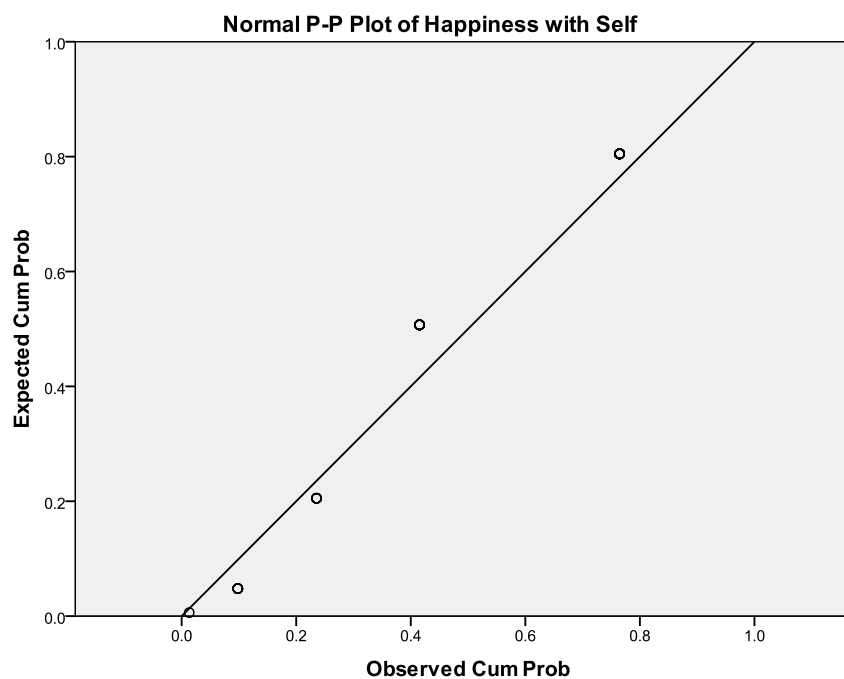


Figure 13.15: P-P Plot of Child Enjoyment

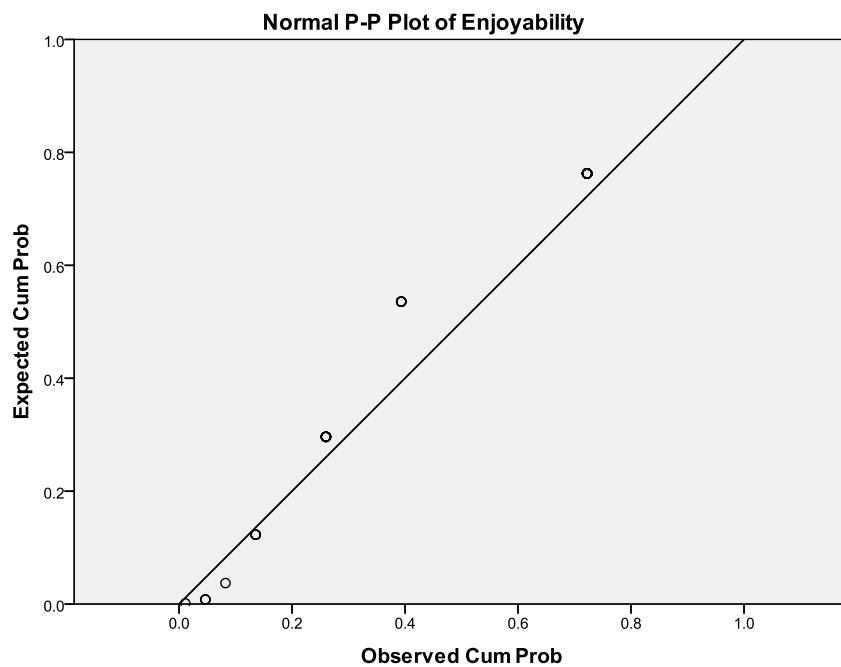
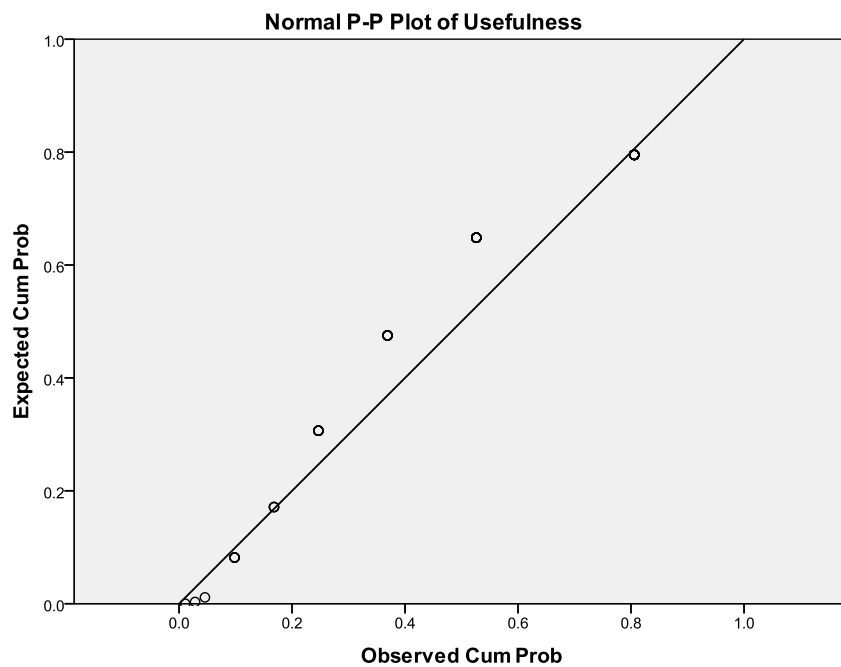


Figure 13.16: P-P Plot of Child Usefulness



Normality: Histograms with normal curve

Figure 13.17: Histogram with normal curve of Noticeability of Cleft Overall

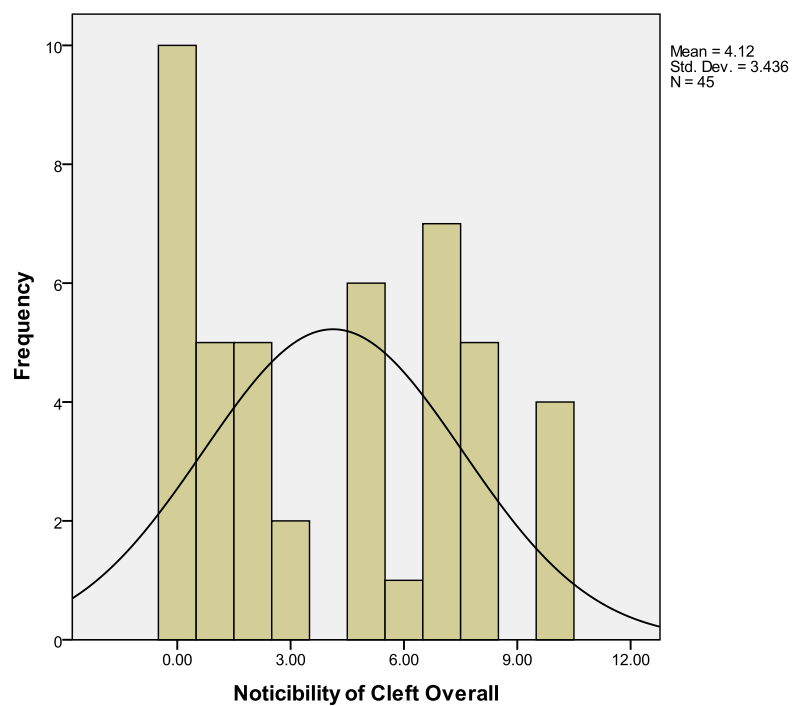


Figure 13.18: Histogram with normal curve of Noticeability of Speech

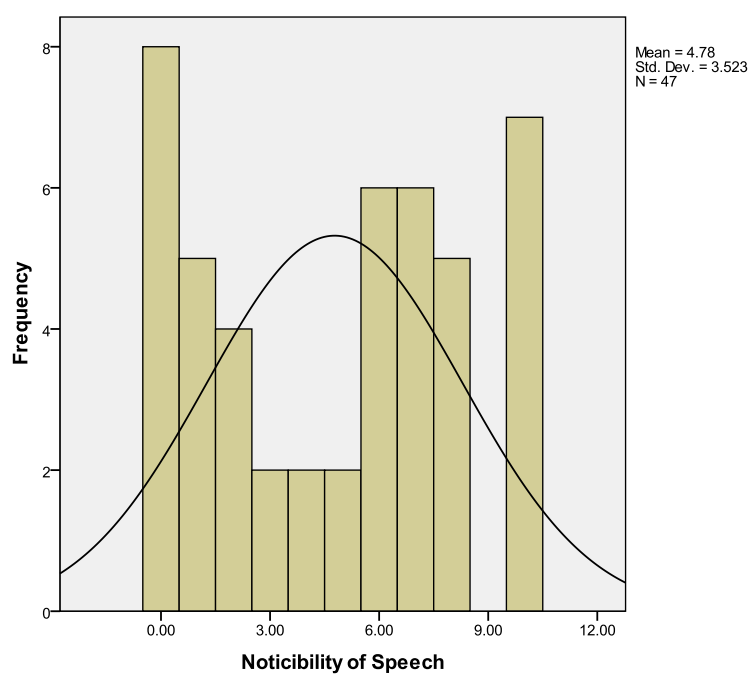


Figure 13.19: Histogram with normal curve of Parental Estimation of Coping in Primary School

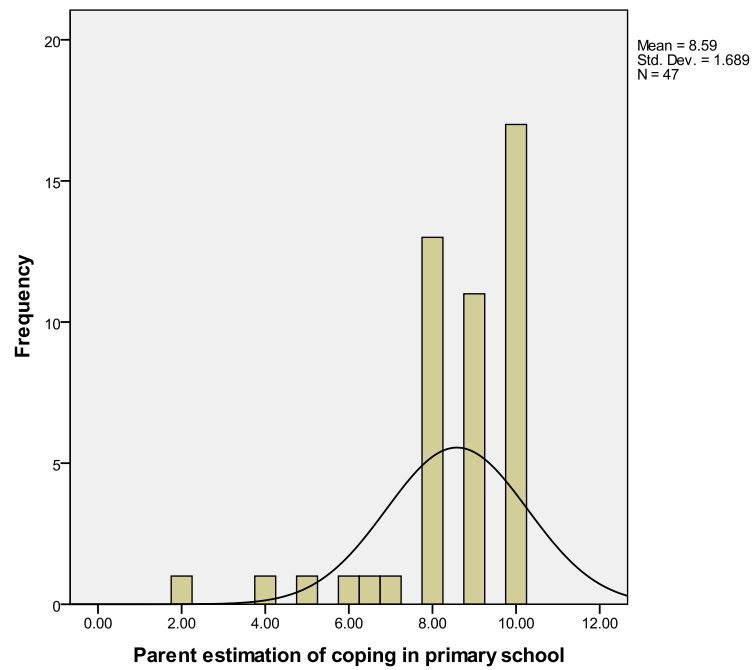


Figure 13.20: Histogram with normal curve of Parental Management of Cleft

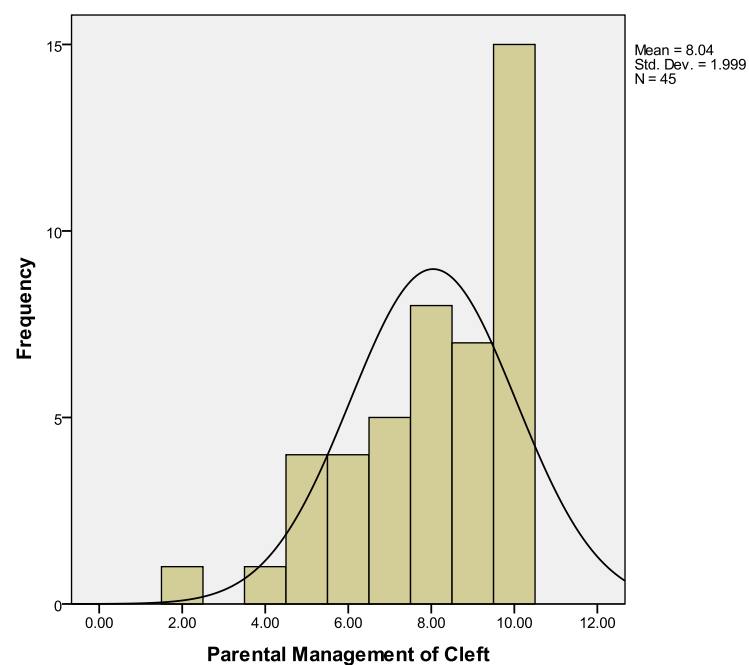


Figure 13.21: Histogram with normal curve of Worry in Relation to Teasing

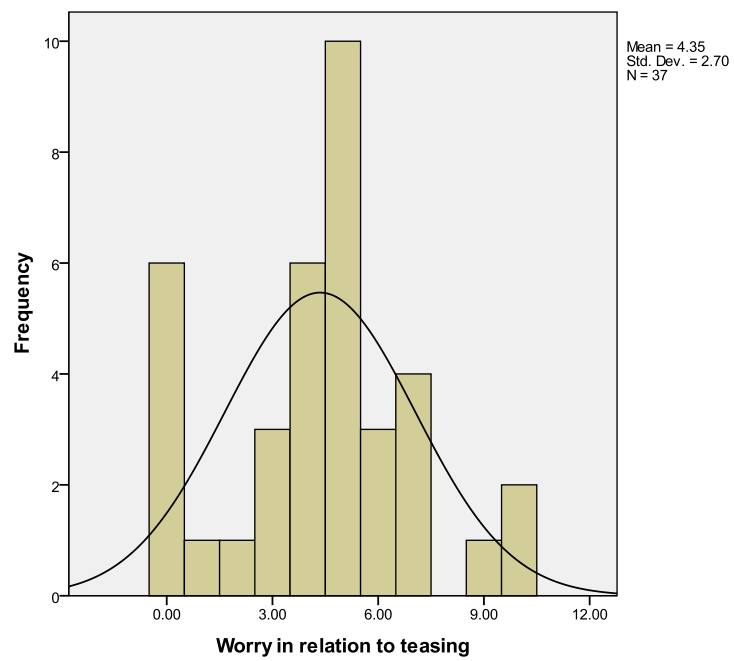


Figure 13.22: Histogram with normal curve of Happiness with Self

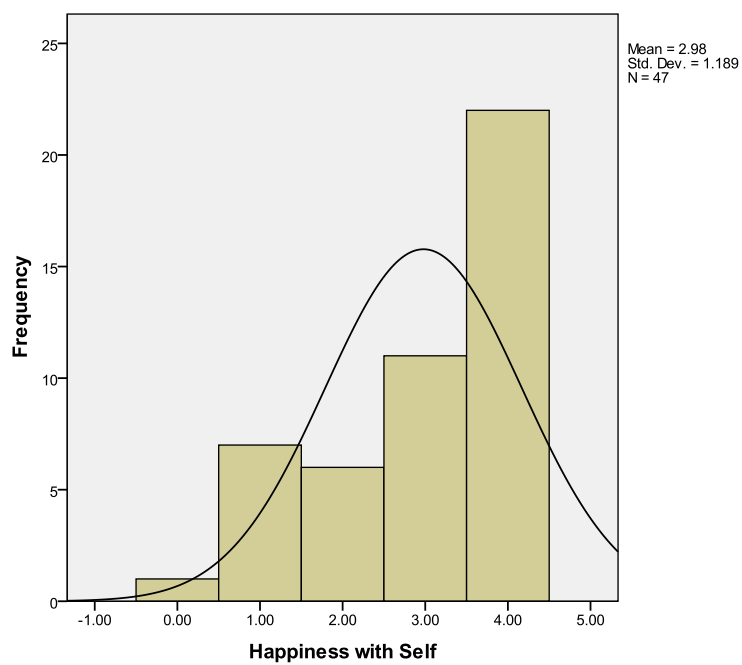


Figure 13.23: Histogram with normal curve of Child Enjoyment

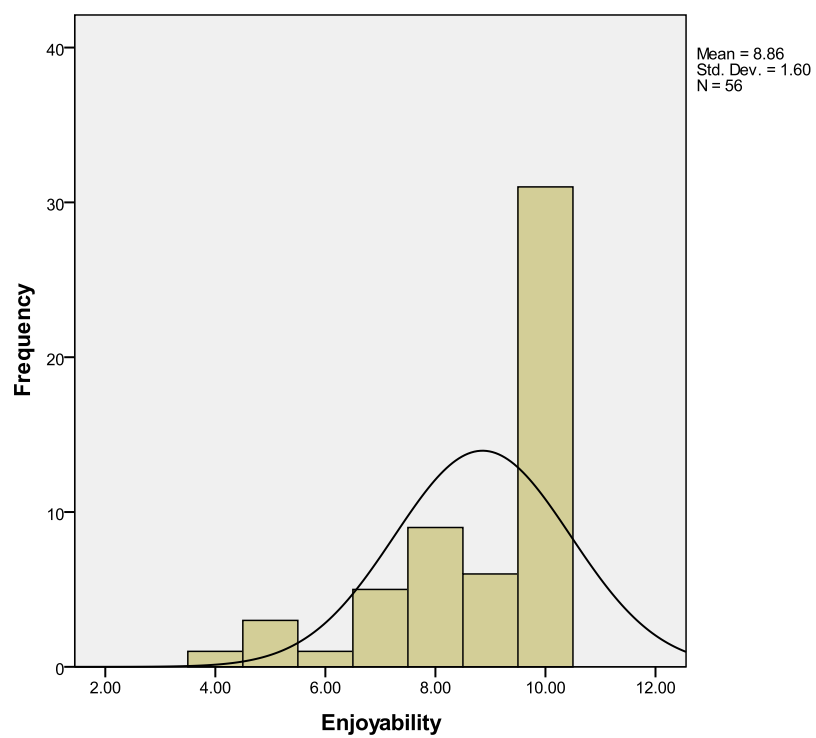
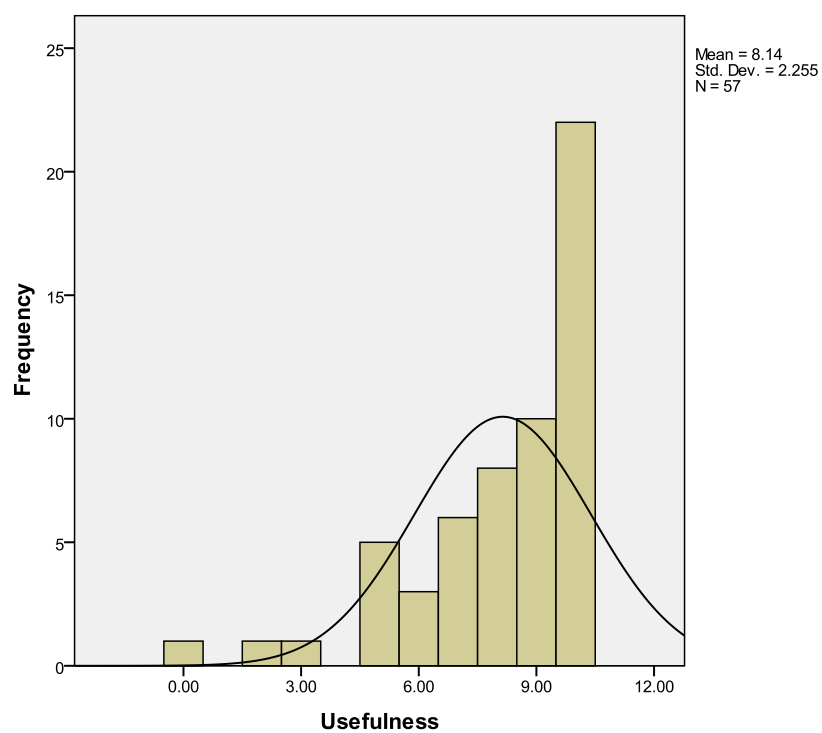


Figure 13.24: Histogram with normal curve of Child Usefulness



Appendix 14: T-tests on Key Variables

Table 14a: Mean and std. Deviation

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Noticibility of Cleft Overall	45	.00	10.00	4.1222	3.43636
Noticibility of Speech	47	.00	10.00	4.7766	3.52292
Parent estimation of coping in primary school	47	2.00	10.00	8.5851	1.68858
Parental Management of Cleft	45	2.00	10.00	8.0444	1.99949
Valid N (listwise)	43				

Table 14b: Independent Sample T-test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Noticibility of Cleft Overall	Equal variances assumed	1.029	.316	-.280	43	.781	-.29630	1.05678	-2.42749	1.83489
	Equal variances not assumed			-.287	39.217	.776	-.29630	1.03376	-2.38691	1.79432
Noticibility of Speech	Equal variances assumed	8.266	.006	-.828	44	.412	-.88207	1.06559	-3.02962	1.26549
	Equal variances not assumed			-.884	43.972	.382	-.88207	.99818	-2.89380	1.12967
Parent estimation of coping in primary school	Equal variances assumed	.396	.532	-.586	44	.561	-.30117	.51431	-1.33770	.73536
	Equal variances not assumed			-.607	43.020	.547	-.30117	.49581	-1.30104	.69871
Parental Management of Cleft	Equal variances assumed	6.918	.012	-3.319	43	.002	-1.80769	.54467	-2.90612	-.70926
	Equal variances not assumed			-3.087	27.741	.005	-1.80769	.58559	-3.00772	-.60767

Appendix 15: Enjoyment and Helpfulness (SPPS)

Table 15a: Descriptive statistics for enjoyment and usefulness for the adults.

	Mean	Std. Deviation	N
Enjoyability	8.7736	1.21910	53
Usefulness	8.6792	1.22118	53

Table 15b: Correlation between enjoyment and usefulness for the adults.

		Enjoyability	Usefulness
Enjoyability	Pearson Correlation	1	.635**
	Sig. (2-tailed)		.000
	N	53	53
Usefulness	Pearson Correlation	.635**	1
	Sig. (2-tailed)	.000	
	N	53	53

** . Correlation is significant at the 0.01 level (2-tailed).

Table 15c: Descriptive statistics for enjoyability and usefulness for the children.

	Mean	Std. Deviation	N
Enjoyability	8.8571	1.60032	56
Usefulness	8.1404	2.25546	57

Table 15d: Correlation between enjoyability and usefulness for the children.

		Enjoyability	Usefulness
Enjoyability	Pearson Correlation	1	.471**
	Sig. (2-tailed)		.000
	N	56	56
Usefulness	Pearson Correlation	.471**	1
	Sig. (2-tailed)	.000	
	N	56	57

** . Correlation is significant at the 0.01 level (2-tailed).

Table 15e: Overall helpfulness

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	1	.9	.9	.9
	2.00	1	.9	.9	1.8
	3.00	1	.9	.9	2.7
	5.00	5	4.5	4.5	7.3
	6.00	5	4.5	4.5	11.8
	7.00	15	13.6	13.6	25.5
	8.00	19	17.3	17.3	42.7
	9.00	23	20.9	20.9	63.6
	10.00	40	36.4	36.4	100.0
	Total	110	100.0	100.0	

Table 15f: Overall Enjoyment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	4.00	1	.9	.9	.9
	5.00	3	2.7	2.8	3.7
	6.00	4	3.6	3.7	7.3
	7.00	10	9.1	9.2	16.5
	8.00	22	20.0	20.2	36.7
	9.00	18	16.4	16.5	53.2
	10.00	51	46.4	46.8	100.0
Total		109	99.1	100.0	
Missing	999.00	1	.9		
Total		110	100.0		

Appendix 16: Reported Concerns (SPPS)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Being Picked on	5	8.3	14.3	14.3
	Starting Secondary School	7	11.7	20.0	34.3
	Not having friends	3	5.0	8.6	42.9
	Appearance	3	5.0	8.6	51.4
	Speech	1	1.7	2.9	54.3
	Homework and school work	4	6.7	11.4	65.7
	What people think	5	8.3	14.3	80.0
	Operations	4	6.7	11.4	91.4
	Sport	1	1.7	2.9	94.3
	Being late	1	1.7	2.9	97.1
	Getting into fights	1	1.7	2.9	100.0
	Total	35	58.3	100.0	
Missing	999.00	25	41.7		
Total		60	100.0		

Appendix 17: Questions, Comments and Responses (SPPS)

Table 17a: Questions about facial appearance in primary school

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	14	23.3	28.6	28.6
	Yes	35	58.3	71.4	100.0
	Total	49	81.7	100.0	
Missing	999.00	11	18.3		
Total		60	100.0		

17b: Type of appearance questions in primary school

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Speech	10	16.7	28.6	28.6
	Facial Appearance	25	41.7	71.4	100.0
	Total	35	58.3	100.0	
Missing	999.00	25	41.7		
Total		60	100.0		

17c: Emotional impact of Questions in primary school

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Not Bothered	12	20.0	33.3	33.3
	Upset	13	21.7	36.1	69.4
	Annoyed	5	8.3	13.9	83.3
	Shy	2	3.3	5.6	88.9
	Happy	1	1.7	2.8	91.7
	Embarrassed	1	1.7	2.8	94.4
	Angry	2	3.3	5.6	100.0
	Total	36	60.0	100.0	
Missing	999.00	24	40.0		
Total		60	100.0		

17d: Reaction to Questions in Primary school

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Explain	25	41.7	71.4	71.4
	Nothing	1	1.7	2.9	74.3
	Walk Away	2	3.3	5.7	80.0
	Deny	1	1.7	2.9	82.9
	Assertive	3	5.0	8.6	91.4
	Ignore	3	5.0	8.6	100.0
	Total	35	58.3	100.0	
Missing	999.00	25	41.7		
Total		60	100.0		

Appendix 18: Gender Differences (SPSS)

Table 18a: Mean and Std. Deviation

	Gender of Child	N	Mean	Std. Deviation	Std. Error Mean
Worry in relation to teasing	Male	22	4.8182	2.46183	.52486
	Female	15	3.6667	2.96808	.76636
Happiness with Self	Male	28	3.0357	1.26146	.23839
	Female	19	2.8947	1.10024	.25241

Table 18b: Independent Samples T-test

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	df	Sig. (2- tailed)	Mean Differen ce	Std. Error Differen ce	Lower	Upper
Worry in relation to teasing	Equal variances assumed	1.107	.300	1.285	35	.207	1.1515 2	.89600	-.66745	2.9704 8
	Equal variances not assumed			1.240	26.349	.226	1.1515 2	.92886	-.75656	3.0595 9
Happiness with Self	Equal variances assumed	.587	.448	.395	45	.694	.14098	.35655	-.57715	.85910
	Equal variances not assumed			.406	42.102	.687	.14098	.34719	-.55964	.84159